



# AirWays

## SERVICE THROUGH EDUCATION AND SUPPORT

Volume 24, Number 2, Mar-Apr 2015

### President's Notes

**Cheryl A. Keeler, President**

Second Wind Lung Transplant Association, Inc.

### Table of Contents

President's Notes.....	1
Second Wind Information .....	2
Every Breath.....	3
Food Safety for Transplant Recipients .....	3
Major Pathogens That Cause Foodborne Illness .....	4
Change of Tacrolimus or Cyclosporine Administration Times on Hospital Admission.....	6
FDA News Release .....	6
Dear Members: Tom Barbour.....	7
Transplant Anniversaries.....	8
Transplant Hero .....	9
Support Group and Events Calendar .....	10
We Remember.....	10
Donations .....	11
New Memberships & Renewals.....	11

**Happy Spring!** The Second Wind Board of Directors hopes that all of you are enjoying the warm Spring weather and are looking forward to the sunny days of Summer. Listed below is an update on the activities of your Board of Directors.

#### AirWays

Thank you to Member and prior Board Member Diane Tefft Young for submitting her article *"The Rest of My Life"* published in the last edition of *AirWays*. After a lung transplant the rest of your life changes significantly for many of us. For some, it is not what we imagined it would be post-transplant, but it is exciting and fulfilling for me. If you would like to share a 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 work on our newly redesigned website is coming to an end. Within the next few weeks a review will be completed and training for the Board of Directors will be completed. We will announce the launch of the new site on our Message Board, E-Mail Support Group and on our Face Book Page so that all of you can log-in and take a look at your new web-site. We plan to also announce the launch date through Constant Contact with an email to our membership. The redesign of your web-site has only been possible as a result of the generous contributions and donations from our membership and corporate sponsors. Thank you so much for all of your support.



#### **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

#### Financial Assistance Program

As a result of your generous donations to the Financial Assistance Program, the Board of Directors was able to provide four (4) Members with financial assistance grants totaling \$1,944.26 through April 2015. These grants were for the following: Temporary Housing- \$1,274.00; Doctor/Hospital Bills- \$44.26; and Transportation Costs- \$226.00. Thank you to all who have made these much needed grants possible.

#### Transplant News

##### • **Walk and Run/Walk Events**

The American Lung Association is sponsoring a series of "Lung Force" walks and run/walk events. The Lung Force walks are a force to be reckoned with regarding lung health for women. According to the American Lung Association every five

(Please see **President's Notes** continued on page 2)

## BOARD OF DIRECTORS

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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.

To submit an article for publication in *AirWays*, send an MS Word document as an attachment to:

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Send hardcopy submissions to the editor:

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*(President's Notes continued from page 1)*

minutes a woman in the United States is told she has lung cancer. The lung cancer death in women has more than doubled in the past thirty-five years. The Lung Force stands together against lung cancer and for lung health. Only a Force of many can stand up to the deadly disease that is COPD; the daily challenges that asthma sufferers face; pollution that threatens our lungs and our lives; and the frightening rise of lung cancer in women. On May 9, 2015 a Lung Force Walk will take place in Cleveland, Ohio at Jacobs Pavilion at Nautica in the Flats, Cleveland, Ohio, and also in Orlando, FL; Denver, CO; Seattle, WA; and Boston, MA. A complete listing of the walks can be found at <http://lungforce.org/walk-events/all>

- **Pulmonary Fibrosis Foundation**

PFF will hold their 2015 Summit on November 12-14, 2015 in Washington, D.C. at the JW Marriott. Information regarding the Summit can be found at [www.jpffsummit.org](http://www.jpffsummit.org)

- **World Transplant Games**

The World Transplant Games (<http://www.wtgf.org>) will take place in Mar del Plata, Argentina, August 23-30, 2015. The games are an international Olympic-style competition for recipients of life-saving transplants and for living organ donors. Athletes compete by gender and age group, from ages under 5 to over 100. The event, along with the Transplant Games of America, focuses on increasing awareness and participation in the worldwide donor registry. According to The World Games website: "Our purpose is to visibly demonstrate the benefits of successful organ transplantation, work to increase public awareness of its success and thereby increase organ donation rates, as well as promote the full rehabilitation and well-being of our participants."

- **UNOS News Bureau**

Modifications to the Lung Allocation Score (LAS) system were implemented on February 19, 2015 by UNOS. The changes included changes in policy and new data variables. The extents of the changes are too lengthy to repeat here in this summary. However, there were lung diseases and their diagnosis groupings added to the four LAS System diagnosis categories. In the LAS system, lung diagnoses are divided into four diagnosis categories: A) obstructive lung disease; B) pulmonary vascular disease; C) cystic fibrosis and D) restrictive lung diseases. Added to group B - pulmonary vascular disease was Pulmonary capillary hemangiomatosis. Added to group D - restrictive lung diseases was the following: Idiopathic interstitial pneumonia (IIP); ABCA3 transporter mutation; Pulmonary lymphangiectasia (PL); Secondary pulmonary fibrosis (specify cause); and Surfactant protein C mutation. Additionally, transplant programs will be able

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

to request an exception from the Lung Review Board to register candidates younger than 11 years, 9 months old with an "other" diagnosis if the candidate's diagnosis is not included in the detailed disease diagnosis list.

We hope you all enjoy a healthy and happy Summer!



## Every Breath

Pam Bland

(Wife and caregiver for Gary Bland, Second Wind  
Director and Treasurer)

I transitioned from "a-sleep-sound-and-wake-up-slow-wife" to one who heard every struggled breath he took. Those long eight hours during his surgery were like difficult gasps for our future. I didn't know if I would ever again hold his warm hand, kiss his lips or laugh at his corny jokes. He had been diagnosed with Idiopathic Pulmonary Fibrosis; the only cure was a transplant. The previous two years we piled oxygen tanks in the hallway, and a fifty foot umbilical cord of air reached wherever he was. I dreaded those twice weekly medical appointments, when I'd drive 40 miles each way over crowded freeways I'd avoided because of my aversion and fear of traffic. This was my initiation as a caregiver. At no time in our thirty-seven years of marriage did I consider this would be the most important job I'd ever grasp with both hands and hold on.

Five hours after being listed as a transplant candidate, he got 'The Call'. The surprise didn't give us worry time, we'd done enough. I threw a generous collection of clean clothes and my pillow in the car. We arrived before midnight, but it was ten long hours before surgery. I climbed into his hospital bed and held on tight. His double lung transplant was a success, and he spent three days in ICU and seven in Telemetry. I was launched into total charge of his aftercare when handed a large brown paper bag of assorted pill bottles, a blood pressure kit, diabetic testers, and directions for the thirty-five daily doses of assorted lifesaving medications, along with the recommended salt-free special high protein diet and warnings regarding three dastardly months of isolation. We left the hospital after requesting an oxygen tank...our security blanket the previous two years. His new lungs frightened us, but this placebo supply of air was to assure everything worked.

The next ninety days were strained. We remained in isolation. Germs weren't allowed. Our children and grandchildren were forbidden. I would make a quick run to replenish the grocery supply then generously splash hand sanitizers before

I touched him. The home aroma went from floral to sterile. Those medications took a toll on sleep. He often roamed the house at night, a problem most transplant patients suffer because of the high doses of prednisone, which also cause 'the moon face.' My immediate personal problems were those specific meals...three a day, seven days a week. I suffered three anxious months before being allowed to enjoy the rest of humanity. Our family visited and we attended our caregiver and patient meetings, which are life savers. Our 'family' became extended and remains an important part of recovery. Some have been lost, but we forever hold their memory in our hearts.

None of these things were in our initial plans. We'd planned to travel and enjoy exotic places. This speed bump just slowed us down and caused us to rearrange our priorities. I will always ask, "Have you taken your pills?" And before visits, we'd always make sure visitors are germ free. We continue to tote bottles of hand sanitizer and patronize restaurants that serve low-salt high-protein meals. Alone on errands I secretly visit a drive-thru and gulp down anything greasy.

We approach our sixth year post-transplant, so is this worth it? My only answer is "Yes...every single minute I hold his hand, kiss his lips and laugh at new wonderful jokes." I intend to be a care-giver for many years.

## Food Safety for Transplant Recipients

Second Wind is pleased to share excerpts from the educational brochure "Food Safety for Transplant Recipients", published by U.S. Department of Agriculture (USDA), Food Safety and Inspection Service (FSIS) in September 2006, slightly revised September 2011. Both agencies are divisions of the U.S. Department of Health and Human Services and the Food and Drug Administration. USDA and FSIS have kindly granted permission for Second Wind to reprint excerpts from this publication. All the information is reproduced verbatim with no editorial changes.

As space permits with each issue I will choose some interesting material to print. The publication is available at no charge by calling 1-888- MPHOTLINE (1-888-674-6854). You can also E-mail [mpholine.fsis@usda.gov](mailto:mpholine.fsis@usda.gov) or [fsis.outreach@usda.gov](mailto:fsis.outreach@usda.gov).

But wait, there's more! Second Wind has acquired a limited number of pamphlets and we are pleased to offer them on a first come basis; when they are gone, they're gone. You can contact the editor, preferably by E-Mail, but snail mail can also be submitted to: [schumann10.ss@gmail.com](mailto:schumann10.ss@gmail.com), or Steve Schumann, 1020 S. Gull Court, Palatine, IL 60067.

This issue's selection is a table summarizing the major pathogens that cause foodborne illness, their most common sources, their pathology, and preventive measures for avoiding infection.

*(Please see Major Pathogens continued on page 4)*

# Major Pathogens That Cause Foodborne Illness

## ***Campylobacter***

### ASSOCIATED FOODS/SOURCES

- Untreated or contaminated water
- Unpasteurized (“raw”) milk
- Raw or undercooked meat, poultry, or shellfish

### SYMPTOMS AND POTENTIAL IMPACT

- Fever, headache, and muscle pain followed by diarrhea (sometimes bloody), abdominal pain, and nausea. Symptoms appear 2 to 5 days after eating and may last 2 to 10 days. May spread to the bloodstream and cause a life-threatening infection.

## ***Cryptosporidium***

### ASSOCIATED FOODS/SOURCES

- Swallowing contaminated water, including that from recreational sources (e.g., a swimming pool or lake)
- Eating uncooked or contaminated food
- Placing a contaminated object in the mouth
- Soil, food, water, and contaminated surfaces

### Symptoms and Potential Impact

- Watery diarrhea, dehydration, weight loss, stomach cramps or pain, fever, nausea, and vomiting; respiratory symptoms may also be present.
- Symptoms begin 2 to 10 days after becoming infected, and may last 1 to 2 weeks. In those with a weakened immune system, including bone marrow and solid organ transplant recipients, symptoms may subside and return over weeks to months.

## ***Clostridium perfringens***

### ASSOCIATED FOODS/SOURCES

- Many outbreaks result from food left for long periods in steam tables or at room temperature and time and/or temperature abused foods
- Meats, meat products, poultry, poultry products, and gravy

### SYMPTOMS AND POTENTIAL IMPACT

- Onset of watery diarrhea and abdominal cramps with 6 to 24 hours (typically 8 to 12). The illness usually begins suddenly and lasts for less than 24 hours. In the elderly, symptoms may last 1 to 2 weeks.
- Complications and/or death occur only very rarely.

## ***Listeria monocytogenes***

*Can grow slowly at refrigerator temperatures*

### ASSOCIATED FOODS

- Improperly reheated hot dogs, luncheon meats, cold cuts, fermented or dry sausage, and other deli-style meat and poultry.
- Unpasteurized (raw) milk and soft cheeses made with unpasteurized (raw) milk
- Smoked seafood and salads made in the store such as ham salad, chicken salad, or seafood salads
- Raw vegetables

### SYMPTOMS AND POTENTIAL IMPACT

- Fever, chills, headache, backache, sometimes upset stomach, abdominal pain, and diarrhea. May take up to 2 months to become ill.
- Gastrointestinal symptoms may appear within 9 to 48 hours, and disease may appear 2 to 6 weeks after ingestion. The duration is variable.
- Those at-risk (including bone marrow and solid organ transplant recipients and others with weakened immune systems) may later develop more serious illness; death can result from this bacteria.
- Can cause problems with pregnancy, including miscarriage, fetal death, or severe illness or death in newborns.

# Major Pathogens That Cause Foodborne Illness

## *Escherichia coli* O157:H7

One of several strains of *E. coli* that can cause human illness

### ASSOCIATED FOODS

- Undercooked beef, especially ground beef
- Unpasteurized milk and juices, like “fresh” apple cider
- Contaminated raw fruits and vegetables, and water
- Person-to-person contact

### SYMPTOMS AND POTENTIAL IMPACT

- Severe diarrhea that is often bloody, abdominal cramps, and vomiting. Usually little or no fever.
- Can begin 1 to 8 days after contaminated food is eaten and lasts about 5 to 10 days.
- Some, especially the very young, may develop hemolytic-uremic syndrome (HUS), which can cause acute kidney failure, and can lead to permanent kidney damage or even death.

## *Noroviruses (and other caliciviruses)*

### ASSOCIATED FOODS

- Shellfish and fecally-contaminated foods or water
- Ready-to-eat foods touched by infected food workers; for example, salads, sandwiches, ice, cookies, fruit

### SYMPTOMS AND POTENTIAL IMPACT

- Nausea, vomiting, and stomach pain usually start between 24 to 48 hours, but cases can occur within 12 hours of exposure. Symptoms usually last 24 to 72 hours.
- Diarrhea is more prevalent in adults and vomiting is more prevalent in children.

## *Salmonella (over 2,300 types)*

### ASSOCIATED FOODS

- Raw or undercooked eggs, poultry, and meat
- Unpasteurized (raw) milk or juice
- Cheese and seafood
- Fresh fruits and vegetables

### SYMPTOMS AND POTENTIAL IMPACT

- Stomach pain, diarrhea (can be bloody), nausea, chills, fever, and/or headache usually appear 12 to 72 hours after eating; may last 4 to 7 days.
- In people with a weakened immune system, such as bone marrow and solid organ transplant recipients the infection may be more severe and lead to serious complications including death.

## *Toxoplasma gondii*

### ASSOCIATED FOODS/SOURCES

- Accidental contact of cat feces through touching hands to mouth after gardening, handling cats, leaning cat's litter box, or touching anything that has come in contact with cat feces.
- Raw or undercooked meat

### SYMPTOMS AND POTENTIAL IMPACT

- Flu-like illness that usually appears 5 to 23 days after eating may last months. Those with a weakened immune system, including bone marrow and solid organ transplant recipients, may develop more serious illness.
- Can cause problems with pregnancy, including miscarriage and birth defects.

## *Vibrio vulnificus*

### ASSOCIATED FOODS

- Undercooked or raw seafood (fish or shellfish)

### SYMPTOMS AND POTENTIAL IMPACT

- Diarrhea, stomach pain, and vomiting may appear within 1 to 7 days and last 2 to 8 days. May result in a blood infection. May result in death for those with a weakened immune system, including people with bone marrow and solid organ transplants, cancer or liver disease.



# Change Of Tacrolimus Or Cyclosporine Administration Times On Hosptial Admission

Marcus Haug III, B.Sc., M.Sc., Pharm.D.

**W**hen you are admitted to the hospital you are asked to change the administration times of your tacrolimus or cyclosporine to 6am—6pm from a 8am—8pm schedule (if taken twice a day) or from a 8am to 6am schedule if you receive the immunosuppressant once a day. This may be of concern for a number of patients for a number of reasons including the feeling that these dose schedules should not be altered or that the day now is starting two hours earlier.

I want to assure lung transplant patients that changing administration time judiciously is not going to affect the health of your lung. My initial discharge teaching after lung transplant includes altered dose administration time scenarios such as occurrence of daylight saving time changes twice a year, what happens if they miss a dose and lastly if traveling takes you out of your current time zone. Of course if you were to change administration times continuously, a detrimental lung function effect is highly likely (we at Cleveland Clinic strive to minimize alterations in immunosuppression exposure by standardizing the dose times of tacrolimus or cyclosporine).

The hospital lung transplant team is striving to give you the timely care you deserve. The change of the morning dose time of tacrolimus, or cyclosporine, to 6am allows your blood levels to be drawn earlier in the day so blood level results are not holding up your care. The hospital blood levels take precedence over the outpatient levels but other hospitalized solid organ transplant patients are also getting their levels measured. The change in hospital dose times, for your tacrolimus or cyclosporine, allows the laboratory the time to deliver timely results that the solid organ transplant teams rely on in making patient care decisions.

*Disclaimer: I refer heavily to medications brand names, even though many of you are on the generic versions. I only do this to decrease the amount of "translation" from longer generic names to shorter brand names which are more often recognized by patients. Psst... Don't report me to my colleagues please.*



Marcus Haug III, B.Sc., M.Sc., Pharm.D.

Dr. Haug received his Bachelor of Science as well as his Master's Degree in Pharmaceutical Sciences from North Dakota State University. He went on to complete a Residency in Clinical Pharmacy at Holy Cross Hospital in Fort Lauderdale, Florida.

Dr. Haug completed his Doctor of Pharmacy degree in 1981 at Purdue University.

In 1987 he accepted the Clinical Pharmacokinetics Specialist position at Cleveland Clinic. Dr. Haug started work with the Lung Transplant Team in 1991 developing immunosuppressant drug dosage and blood level guidelines obtained by observing the clinical pharmacology in this population of transplants.

Dr. Haug is a contributing author on over 60 articles and abstracts featured in the medical, pharmacology and pharmaceutical literature.



Marcus Haug III



## FDA News Release

FDA approves donor lung preservation device that may result in more lung transplants  
August 12, 2014

**T**oday, the U.S. Food and Drug Administration approved the XVIVO Perfusion System (XPS) with STEEN Solution, a device for preserving donated lungs that do not initially meet the standard criteria for lung transplantation but may be transplantable if there is more time to observe and evaluate the organ's function to determine whether the lung is viable for transplantation.

*(Please see FDA continued on page 7)*

# Dear Fellow Second Wind

## Members:

**I**t is with deep sadness that I must report the passing of one of our prior Board Members; Thomas Barbour. I'm sure that many of you knew Tom. He posted regularly on our Internet E-mail Support Group and was always willing to share his time and experience with all of us.

Tom first joined Second Wind on August 13, 2009. In 2008 Tom was diagnosed with IPF and after two dry-runs, received a bi-lateral lung transplant at Temple University Hospital on January 18, 2011. Early on Tom had several complications that delayed his release from the hospital and his recovery. But, as he said many times, his transplant team was prepared to deal with each of the complications and they did a superb job of getting him through it all.

When Tom first joined Second Wind he began posting on the Internet E-mail Support Group. He shared his own experiences with others facing lung transplantation and was always upbeat and positive. Even prior to his transplant, he didn't give up hope and offered kind and supportive words to others.

After Tom's transplant he wanted to "spread the word" as he put it and encourage organ donor registration. He often delivered talks to fraternal organizations and community groups. Tom served as Chairman of the NY Masonic Grand Lodge Organ Donor Awareness Program, which assisted five ODOs in New York with their efforts to increase donor registrations.

In an effort to continue to give back to the transplant community, Tom joined the Board of Directors of Second Wind on June 14, 2012. While on the Board, Tom served as the Liaison Program Director. As the Director of the Liaison Program, Tom organized and recruited liaisons for the many lung transplant centers across the country. Tom would talk with Second Wind Members, and recruit them to become Liaisons at their own transplant centers so that they would be able to introduce new patients to Second Wind. Tom also served as a Mentor in Second Wind's Peer Support Program.

Tom was a kind and giving man to all in the transplant community. He was always willing to share his time and never complained. His passing came as a shock to many of us even though we knew he was fighting chronic rejection. We were blessed to have known him and are grateful to him and his family for all of the time and commitment he shared with us and all of our Members. He is truly missed. Tom died of chronic rejection on February 27, 2015.

(I must end this article as Tom would have.)

Ciao,  
Cheryl Keeler, President  
Second Wind



Tom Barbour

*(FDA continued from page 6)*

Lung transplantation is a primary option in the care of patients with end-stage chronic lung diseases, such as chronic obstructive pulmonary disease, cystic fibrosis and idiopathic pulmonary fibrosis. Approximately one in five donated lungs meets the standard criteria for a donor lung and is transplanted into a recipient. In 2012, 1,754 lung transplants were performed in the United States and at the end of that year, 1,616 potential recipients remained on the waiting list.

"This innovative device addresses a critical public health need," said Christy Foreman, director of the Office of Device Evaluation at the FDA's Center for Devices and Radiological Health. "With this approval, there may be more lungs available for transplant, which could allow more people with end stage lung disease who have exhausted all other treatment options to be able to receive a lung transplant."

If additional time is needed to determine if a donated lung meets the standard criteria for lung transplantation, the XPS can be used to warm the donor lungs to near normal body temperature and continuously flush the lung tissue with a sterile fluid solution, called STEEN Solution, which preserves the lungs and removes waste products. The XPS also ventilates the lungs, which oxygenates the cells and makes it possible for the transplant team to examine the lungs' airways with a bronchoscope. Donor lungs can stay in the machine

*(Please see FDA continued on page 8)*

# Transplant Anniversaries

APRIL 2015

## FEBRUARY 2015

Name	Transplant Date	Yrs
Maria Loss	2-1-2008	7
Karen Ettinger	2-1-2012	3
<b>Sandra Andersen</b>	<b>2-3-2001</b>	<b>14</b>
<b>Cheryl Keeler</b>	<b>2-3-2005</b>	<b>10</b>
Ross Pope	2-10-2014	1
Susan Sweeney	2-10-2014	1
Starla Sage	2-12-2011	4
Everett Johnson	2-14-2006	9
<b>Martha C Becker</b>	<b>2-16-2004</b>	<b>11</b>
Peg Matthews	2-16-2010	5
<b>Robert Hutcherson</b>	<b>2-23-2001</b>	<b>14</b>
Roger Trail	2-27-13	2

## MARCH 2015

Name	Transplant Date	Yrs
<b>Stacy T. Veasey</b>	<b>3-14-2005</b>	<b>10</b>
Donald Poole	3-14-2012	3
Nikki Addison	3-16-2013	2
Robert Kevin King	3-20-2008	7
Angus McDonald	3-21-2010	5
John Jordan	3-21-2010	5
<b>Darcy Shaw</b>	<b>3-23-2005</b>	<b>10</b>
<b>Kathryn Flynn</b>	<b>3-25-1996</b>	<b>19</b>
<b>William McAuley</b>	<b>3-23-2005</b>	<b>10</b>
Sharon Andrews	3-2-2012	3
<b>Paula Huffman</b>	<b>3-29-1999</b>	<b>16</b>

Name	Transplant Date	Yrs
Aharon Taus	4-3-2007	8
Gary Bland	4-7-2009	6
James Zackavec	4-11-2013	2
Kenneth Carrell	4-12-2008	7
Gary Koerlein	4-17-2011	4
<b>Carrol Litwin</b>	<b>4-22-2005</b>	<b>10</b>
<b>Greg Briggs</b>	<b>4-30-1997</b>	<b>18</b>
<b>Frederick Rasmussen</b>	<b>4-30-2005</b>	<b>10</b>

*(FDA continued from page 7)*

for up to four hours; during this time the transplant team can examine the lungs and evaluate their function. If after further evaluation the lungs meet certain functionality criteria, and pass the transplant surgeon examination, they are transplanted into a recipient.

The XPS received a Humanitarian Use Device (HUD) designation and was reviewed through the Humanitarian Device Exemption (HDE) pathway. A HUD is a device which treats or diagnoses a disease or condition affecting fewer than 4,000 individuals in the United States per year. In order to receive this type of approval, a company must demonstrate, among other things, safety and probable benefit, i.e., that the device will not expose patients to an unreasonable or significant risk of illness or injury, and that the probable benefit of the device outweighs the risk of illness or injury. In addition there can be no legally-marketed comparable devices, other than another HDE, available to treat or diagnose the disease or condition.

The FDA's review of the XPS included two clinical trials supporting the safety and probable benefit of the device. Both trials compared outcomes of lung transplant patients who received non-ideal donor lungs preserved using ex vivo lung perfusion with STEEN Solution to lung transplant patients who received ideal donor lungs that were preserved using conventional cold storage techniques. Both trials showed that recipients of the ideal and non-ideal lungs had similar survival rates up to 12 months after transplant and similar rates of organ rejection. As a condition of approval, the manufacturer will conduct a post-approval study of the long-term effects of the device and adverse events.

*Congratulations to all who celebrate another milestone!*

*(Please see FDA continued on page 9)*



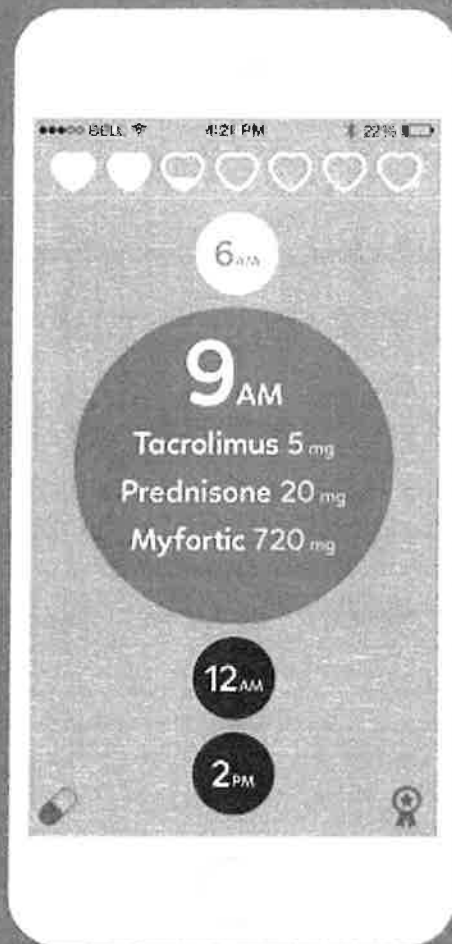
# Transplant Hero

Dr. Jay Graham, MD

I am a transplant surgeon in NY and I developed an app to help patients remember to take their immunosuppression medications. Transplant Hero is a beautifully created App that helps transplant patients deal with the seemingly impossible task of taking their immunosuppression medications in a timely fashion.

At the core, Transplant Hero is an alarm system that alerts the user when it is time to take their medication. However, Transplant Hero is so much more! It is an interactive, educational and simple to use tool that offers users positive reinforcement for medication adherence.

In talking to patients over the years, it has become evident that taking medication is not easy. First of all, there are so many! Secondly, these medications apparently need to be taken at all hours of the day and night.



Check your immunosuppression regimen at a glance



Transplant Hero clears up the confusion by focusing on some of the most important medications and timing them appropriately — so you don't have to! As you know, serious problems can arise due to medication non-adherence. For this reason if you have a transplant, you need Transplant Hero — because everyone needs a helping hand!

I essentially made “Transplant Hero” because as a clinician I recognized how hard it was sometimes for patients to remember to take their immunosuppression. At times, life just gets in the way. In any case, check it out...it's totally free.

Jay A. Graham, MD

Transplant Hero LLC

“Everyone needs a helping hand”

[www.transplanthero.com](http://www.transplanthero.com)

*(Second Wind has no affiliation, endorsement, or business relationship with Transplant Hero LLC. This information is printed solely because it may be of interest to the transplant community.)*

# Support Groups & Events Calendar

**Air Ways** 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,  
slongng@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

### 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)



*(FDA continued from page 8)*

The XVIVO Perfusion System with STEEN Solution is manufactured by XVIVO Perfusion, Inc., of Englewood, Colorado.

The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices. The agency also is responsible for the safety and security of our nation's food supply, cosmetics, dietary supplements, products that give off electronic radiation, and for regulating tobacco products.



## WE REMEMBER

Tom Barbour

Vestal, NY

Date of Birth: February 16, 1940

Bilateral, Lung Transplant, January 18, 2011

Temple University Hospital

Date of Death: February 27, 2015

Norma Watson

Kodak, TN

Date of Birth: November 28, 1937

Single Lung Transplant, April 26, 2003

Vanderbilt University Medical Center

Date of Death: February 3, 2015

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

## New Members and Membership Renewals February 2014 – April 2015

### NEW MEMBERS

Ghizlane Benazzi	Sam Eklund
Yvonne Harris	John Hughes
Wanda Jackson	Shaaryn Kane
Jackie Moody	Ernest Ray, Jr.
Maria Trevino	

### RENEWALS

Danny Barnes	Carolyn Blaylock
Barbara Borowski	Michael Brunick
Betsy Cichon	Brian Conley
Diane Desiderio	Kevin Gargan
Sandra Gray	Dave Griggs
Gwen Herron	Edna May Holden
Paula Huffman	Karen Jacobson
Everett Johnson	Terry Johnson
John Jordan	Cheryl Keeler
Robert King	Robert Klein
Kathy Lewis	Peg Matthews
Cathy McGill	Paula Moscariello
Michael Pazen	Amorett Pitrone
Ross Pope	Jim Powers
Darcy Shaw	Susan Sweeney
Karen Swenson	Aharon Taus
Michael Thomas	David Yennior

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

Karen Jacobsen	John Jordan
Adobe Matching (on behalf of Scott Larrimer)	
Michael Thomas	Cheryl Keeler
Betsy Cichon	Karen Swenson
Paula Huffman	

### Donations for Financial Assistance Fund

John Jordan

### Donations for Membership Fund\*

John Jordan	Jim Powers
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\* 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.

## CORPORATE DONATIONS

The Second Wind Board of Directors is delighted to accept corporate sponsorships to help support our mission and goals.

### WILLIAM AND SCOTT LANGE

### THE LANGE GROUP AT MORGAN STANLEY

and

### ALLSTATE INSURANCE COMPANY

Both of these well known companies have made very generous donations to our Financial Assistance Fund.

Thank you so much for your contributions from the Board of Second Wind and from our members who will benefit directly from your generosity.

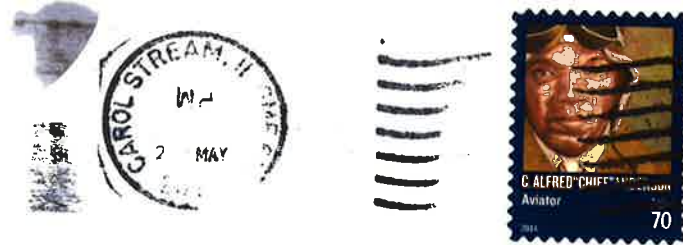




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Family & Colleagues**

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

**RETURN SERVICE REQUESTED**



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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

### **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 Rm 7710  
5700 S. Ellis Ave, Chicago, IL 60637

Contact: Kaitlin Ray, LCSW

[kaitlin.ray@uchospitals.edu](mailto: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](mailto:Apryl.Todd@ucsfmedctr.org)