

Vol. 26 - No. 5 Dec. 2016 - Apr. 2017

Table of Contents

The Importance of Pulmonary Rehabilitation in Lung Transplant Programs	1
Second Wind Information	2
President's Notes	2
Understanding Lung Transplant Rejection	5
Celebrating Life Post-Transplant	6
2017 Hike for Lung Health	6
Second Wind's Newest Board Member.	7
Transplant Anniversaries	8
Support Groups & Events Calendar.	10
New Members and Membership Renewals	11
Donations	11
We Remember	11

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:

keelerc768@aol.com

Thank you!
The Editor

The Importance of Pulmonary Rehabilitation in Lung Transplant Programs

Submitted By: Nadia Long, BS, CTTS
Exercise Physiologist and Certified Tobacco Treatment Specialist
Outpatient Pulmonary Rehabilitation
The Ohio State University Wexner Medical Center
Columbus, Ohio

In a statement by the American Thoracic Society and European Respiratory Society, Pulmonary Rehabilitation is defined as a "comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education, and behavior change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviors." Although pulmonary rehab does not reverse lung disease, participation in such programming can decrease respiratory symptoms such as dyspnea, as well as decrease hospitalizations for patients with chronic lung disease. Rehab participation can also increase health-related quality of life and improve the functional status of these patients.



Nadia Long, BS, CTTS

Despite vast benefits, pulmonary rehab programming continues to be a fairly unfamiliar and underutilized service. Pulmonary rehab programs offer patients the ability to exercise in a monitored, controlled environment under the supervision of pulmonary rehab staff, such as nurses, respiratory therapists, and exercise physiologists. Rehab programs operate under the direction of physicians and advanced practice professionals to ensure the safety and suitability of participants in the rehab program.

The majority of rehab programs are structured as group classes that meet two to three days per week with an average length of eight to twelve weeks or longer. Most sessions include thirty to sixty minutes of supervised exercise plus education regarding the management of chronic lung disease. Exercise training in pulmonary rehab is structured to include cardiovascular exercise to help increase exercise tolerance and improve endurance and symptoms of fatigue. Strength training is also typically incorporated to help with muscular strength and endurance and is particularly helpful for pulmonary patients due to the effects of chronic oral steroid use associated with increased risk of osteoporosis. Stretching, balance exercises stairs and gait training, and well as core strengthening and other functional exercises can be provided in rehab based on the patient's goals.

(Please see *Pulmonary Rehab* continued on page 3)

BOARD OF DIRECTORS

Cheryl A. Keeler, B.A., President
Frank Shields, B.S./B.A., VP
Steve Schumann, B.S., R.Ph., VP
Gary Bland, B.S., M.B.A., Treasurer
Jane Kurz, Ph.D., R.N., Secretary
Tom Archer, M.Ed.
Julie Martin, Peer Support Coordinator &
Garry Nichols, B.S., Ch.E., M.B.A.
Ross Pope, B.S., Marketing
e-Mail Support Group Coordinator
Eric Harned, B.A., Marketing and Management

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:

keelerc768@aol.com

Send hardcopy submissions to the editor:

Cheryl A. Keeler

Second Wind Lung Transplant Association Inc.

2781 Chateau Circle

Columbus, OH 43221

Toll free: 1-888-855-9463

E-mail: keelerc768@aol.com

President's Notes

Cheryl A. Keeler

Second Wind Lung Transplant Association, Inc.

The Board of Second Wind hopes all of you are enjoying the Spring weather and the sunshine. We want to bring you up-to-date on the activities of the last few months and share information on some upcoming events.



AirWays

First, we want to apologize for the delay in getting this edition of *AirWays* to you. We have had some health problems that slowed down the production. We would like to publish some articles about your transplant journey. If you are willing to tell your transplant experience, please write your story and email a copy, along with your picture, to me at keelerc768@aol.com.

The Board wants to take this opportunity to thank our fellow Board Member and Editor of *AirWays*, Steve Schumann. For several years Steve has been the sole Board Member responsible for gathering articles both from members and professional health care providers to publish in our newsletter. Our newsletter is mailed to our members and also several copies are mailed to seventy-five (75) transplant hospitals / centers in the United States. Making sure the addresses are accurate and we have the proper person identified at the transplant center to receive copies of *AirWays* so that it is provided to patients, is a stressful and ongoing job. Steve has done an excellent job for the Board of Directors and our Membership. He certainly deserves a break from this responsibility. For now, articles written for your newsletter will come to me at keelerc768@aol.com. If you want to volunteer to help with the newsletter, please drop me an email. We would be grateful for the assistance.

Financial Assistance Program

Since the last edition of *AirWays*, the Board had processed four (4) requests for financial assistance from our membership. The total amount paid was \$1,150.00. These grants covered transportation costs to and from the member's transplant center, a month's rent for temporary housing; and, prescription co-pays. Thank you to all of you who made donations to our Financial Assistance Program.

Later in this edition of *AirWays* you will find information on our annual fund raiser: Hike for Lung Health. Please read the information and register to participate in this event either in

(Please see *President's Note* continued on page 4)

The exercise component of pulmonary rehab can be overwhelming to a lot of patients, especially those with extremely debilitating dyspnea or those with high oxygen requirements. Rehab staff conducts a thorough initial assessment and functional testing, such as a six-minute walking test, to assist in developing an appropriate exercise plan for each patient. Staff can further personalize these exercise plans based on the patient's activity level prior to starting rehab and any physical limitations or comorbid conditions.

In years past, pulmonary rehabilitation targeted referrals and participation mainly for patients with Chronic Obstructive Pulmonary Disease (COPD). In more recent decades, pulmonary rehab has evolved to include patients with non-COPD types of lung disease, including but not limited to restrictive lung diseases, interstitial lung diseases, and pulmonary hypertension as well as pre and post lung surgery patients.

The main benefits of rehab are the same among COPD and non-COPD patients, however programming can be tailored to touch on disease-specific topics relating to these patients, such as long-term oxygen therapy, medication management and airway clearance, along with behavioral and nutritional interventions. With the growth of surgical tracks like Lung-Volume Reduction Surgery (LVRS) and lung transplantation programs, pulmonary rehab is highly recommended and even required by some health systems for patients undergoing evaluation as well as in the post-operative period.

The rehab-specific benefits for surgical patients relate to optimizing physical preparation before and accelerating recovery after surgery. Rehabilitation goals for patients being evaluated for or listed for lung transplant include physical conditioning that focuses on enhancing and maintaining functional status prior to transplant. Pre-transplant rehab can also help these patients meet and maintain specific criteria for transplant, such as a required six-minute walking distance or body weight as determined by each program. Patients should be encouraged to strive for twenty to thirty minutes of continuous aerobic exercises, like walking or biking, to help with muscular endurance.

Some pre-transplant patients may require implementation of interval training if they are unable to sustain continuous bouts of exercise. Interval training allows patients to vary their intensity of exercise or rest for brief periods while performing these activities. This style of training can be especially beneficial for those patients with severe deconditioning, limiting dyspnea, or significant oxygen desaturation during exercise. All pre-transplant patients should be encouraged to focus on lower body endurance and quadriceps strengthening

One solution for oxygen at home, away, and for travel

INTRODUCING THE INOGEN ONE

It's oxygen therapy on your terms

NO MORE TANKS TO REFILL.

NO MORE DELIVERIES.

NO MORE HASSLES WITH TRAVEL.

The **Inogen One portable oxygen concentrator** is designed to provide unparalleled freedom for oxygen therapy users. It's **small, lightweight, clinically proven** for stationary and portable use, during the day and at night, and **can virtually go anywhere - even on most airlines**. Inogen accepts Medicare and many private insurances!



Only 4.8 pounds!

Covered by Medicare

FAA Approved for Airline Travel



FREE INFO KIT

inogen

oxygen. anytime. anywhere.®

Free Info Kit Coupon

Call Inogen Today to Request Your **FREE** Info Kit

1-800-966-5484

Reclaim Your Freedom and Independence



activities such as stair training and exercises like chair squats and leg lifts. These exercises can be very beneficial during the transplant preparation phase to help minimize post-transplant leg weakness and fatigue, which are common complaints. Regular physical activity gained by engaging in a pre-transplant rehab program should be followed by routine exercise at home or in a pulmonary rehab maintenance program after rehab "graduation." Pre-transplant patients are highly encouraged, and in some programs required, to continue regular exercise up until time of transplantation to help maintain their functional status.

While lung transplantation eliminates ventilatory limitations it does not eliminate the need for rehabilitation following surgery. Immediate post-transplant rehabilitation in the hospital setting is recommended and implemented to help patients regain independence with self-care activities and encourage early mobilization. Inpatient rehab staff work with patients to help them ambulate safely with consideration for chest tubes, IV's, and other equipment the patient might require.

Walking early and often in the hospital can help reduce the risk for blood clots and infections as well as help with improving functional status following transplant. Longer or more complicated hospital stays may result in admission to a skilled

*(Please see **Pulmonary Rehab** continued on page 7)*

Chicago, Illinois, or as a virtual walker in your home city. If you are unable to participate as a walker, please support Team Second Wind by making a donation in support of your team.

Transplant News

The Pulmonary Fibrosis Foundation (PPF) had announced the PPF Summit for 2017. The Summit provides an opportunity to meet physicians, researchers, patients, caregivers, lung transplant recipients, individuals who has lost a loved one, industry representatives and members of the international PF community. The goal of the Summit is to foster a collaborative environment to improve education and awareness of PF and to identify new approaches to treat, and ultimately cure, this devastating disease. New to the 2017 Summit is separate programming for those who are newly diagnosed and their families, those who have been living with PF and already understand the basics, and those who have lost a loved one or who have received a lung transplant.

The Summit will be held in Nashville, Tennessee on November 9-11, 2017 at the Omni Nashville Hotel, phone number 615-782-5300. For more information about the PPF Summit, including a program overview, hotel information and more, please visit web site: www.pffsummit.org.

United Network for Organ Sharing (UNOS)

UNOS reported a new record high for organ transplants performed in the United States in 2016. For 2016, 33,606 transplants were reported which represents an 8.5% increase over the 2015 total and an increase of 19.8% since 2012. According to Stuart Sweet, M.D., PhD, President of the OPTN/UNOS Board of Directors, "thousands more men, women and children are receiving a life-saving transplant opportunity each year." "This increase in organ transplants is partly a realization of an ongoing commitment to improvement at organ procurement organizations, and transplant hospitals, said Brian Shepard, UNOS Chief Executive Officer."

United Network for Organ Sharing (UNOS) serves as the Organ Procurement and Transplantation Network (OPTN) by contract with the U.S. Department of Health and Human Services Administration, Division of Transplantation. The OPTN brings together medical professionals, transplant recipients and donor families to develop national organ transplantation policy.

American Lung Association

The American Lung Association (ALA) announced they are investing more than \$6.38 Million dollars in fiscal year 2017. In a press release ALA announced they will continue efforts to advance research for all lung diseases and reduce the burden of lung disease on individuals and families by funding more

than \$6.38 million in grants in fiscal year 2016-2017, almost \$2 million of which is for newly awarded research on lung disease through the nationwide Awards and Grants Program.

Currently the ALA is funding a total of 68 research projects at 50 institutions throughout 24 states. Newly funded research includes some of the following projects.

- Identifying signaling mechanisms driving lung cancer invasion
- Integrating smoking cessation interventions into lung cancer screening, which could potentially help reduce the risk of lung cancer
- Revealing the genomic determinants of death and disease progression in patients with IPF

In addition to the above, the Lung Association funds the Airways Clinical Research Center Network (ACRC), the nation's largest not-for-profit network of clinical research centers dedicated to asthma and COPD treatment research.

The ALA released their 8 tips to quitting smoking for good in 2017 - these tips included the following:

- 1 **Eliminate triggers.** Do a thorough cleaning of your house and take care to remove cigarettes, ashtrays, smoke odors and other reminders of smoking. If you live with someone who smokes and is not quitting at this time, make a plan so you're not tempted when they light up. Ask them not to smoke in front of you, at least during the toughest parts of your quit.
- 2 **Give it time.** The desire to smoke won't disappear overnight and the first 7 to 10 days will probably be the toughest. Most smokers who return to smoking do so within the first 3 months. Even after several months or years, you may still have occasional cravings for a cigarette. This is normal. These urges will occur less often over time.
- 3 **Slip-ups are OK.** Nobody is perfect and your path to quitting might not be either. Having a puff or smoking a cigarette or two doesn't have to mean you're done with the quit attempt. If you have a small lapse - you haven't failed as long as you take action to prevent it happening again. Remind yourself of all the good reasons why you decided to quit and figure out what you'll do differently moving ahead. Be patient with yourself and keep looking forward.
- 4 **Wait it out.** A craving to smoke only lasts three to five minutes, whether you smoke or not. Call a friend, get a drink of water, do some deep breathing or play a game on your phone. Find something to distract your mind so you can make it through those few minutes.

(Please see President's Note continued on page 8)

Understanding Lung Transplant Rejection

By Dr. Ramsey Hachem

Medical director of the Lung Transplant Program
at Barnes-Jewish Hospital.



Rejection remains a significant problem after lung transplantation in spite of advances in induction and maintenance immunosuppressive regimens over the past 25 years. Failure of the transplanted lungs is a leading cause of death at all time points after transplantation, and this is often a result of rejection.

There are different forms of rejection that may occur at different time points after transplantation, and these have a different impact on the clinical course. This column will highlight these different forms of rejection and their typical treatments.

Acute rejection typically occurs in the first 6 to 12 months after transplantation. This form of rejection often does not cause any symptoms, and when symptoms are present these are typically non-specific. In other words, symptoms associated with acute rejection can be seen with other complications such as infections. As a result, the diagnosis requires a lung biopsy, which can be performed through bronchoscopy. The characteristic finding on a lung biopsy is a collection of immune cells surrounding small blood vessels. The grade of rejection depends on the severity of inflammation around small vessels and whether other parts of the lungs are involved. Although acute rejection is treatable and completely reversible with treatment, it is an important risk factor for chronic rejection. In addition, approximately 40% of patients experience at least one episode of acute rejection. As a result, most transplant centers perform surveillance bronchoscopy and lung biopsies in the first year to identify acute rejection early and treat it with the hope of decreasing the risk of chronic rejection.

The most common treatment is a 3-day course of high-dose intravenous steroids. In some cases, the maintenance dose of prednisone is increased then tapered. In general, a follow-up bronchoscopy and lung biopsy are performed 3-8 weeks later to make sure rejection is not persistent. In cases of persistent rejection, more intensive immunosuppression is necessary. There are multiple options including another course of high-dose intravenous steroids and a course of anti-thymocyte globulin.

Antibody-mediated rejection has been an increasingly recognized form of lung rejection over the past 5 years. Historically, our understanding of antibody-mediated rejection after lung transplantation was limited to hyperacute rejection, which occurs immediately following transplantation as a result of pre-formed antibodies to mismatched human leukocyte antigens (HLA). With advances in HLA antibody detection

testing, hyperacute rejection has become rare in the past years. However, we have recognized cases of antibody-mediated rejection at later time points after transplantation.

Although this form of rejection is rare, it often results in severe lung injury, which may be fatal in some cases. The diagnosis of antibody-mediated rejection is difficult requiring collaboration between clinicians, pathologists, and HLA lab specialists. In addition, treatment of antibody-mediated rejection is difficult and the response to treatment is limited. Thus far, the best regimen for the treatment of antibody-mediated rejection remains unknown, but treatment is focused on depleting antibodies, stopping the production of additional antibodies, and blocking the effect of antibodies on the lung. This requires multiple medications and sometimes the use of plasma exchange, which is a treatment that removes antibodies from the circulation. In spite of aggressive therapy, antibody-mediated rejection does not respond well. In some cases, this rejection is completely reversible, but in others there is persistent lung damage and scarring that may progress to chronic rejection. Much remains to be learned about antibody-mediated rejection and its management.

Chronic rejection is the leading cause of death beyond the first year after lung transplantation. Unfortunately, this is a common complication occurring in approximately 50% of recipients within 3-4 years of transplantation. The characteristic pathology of chronic rejection is obliterative bronchiolitis. This represents scarring of the small airways in the lungs that obstructs their lumen. The initial clinical manifestations of chronic rejection include a decline in lung function (spirometry) and breathlessness with exertion. Lung biopsies obtained during bronchoscopy yield small pieces of tissue that often don't show the characteristic pathology of chronic rejection. Nonetheless, bronchoscopy and lung biopsies are generally done if there is a decline in lung function to exclude other potential causes and identify possible infections that would require treatment before more intensive immunosuppression. First line therapy for chronic rejection is azithromycin three times weekly. Although azithromycin is an antibiotic, it has immune modulating effects that are sometimes effective in the treatment of chronic rejection. However, many patients don't respond to azithromycin and additional therapy is necessary. There is no consensus regarding the best second-line therapy and different programs have different approaches. These include a course of anti-thymocyte globulin, substituting sirolimus or everolimus for mycophenolate, and extracorporeal photopheresis. Different patients have different responses to these alternatives, but predicting who will have a favorable response to any specific therapy remains unclear.

Although we have learned a great deal about different forms of rejection over the past 25 years, chronic rejection remains the leading obstacle to better outcomes after lung transplantation. Clinical trials that critically assess the efficacy and safety of different regimens are necessary to improve outcomes.

This article is reprinted with the permission of the St. Louis Chapter of Second Wind, with our thanks and gratitude to the Chapter and to Dr. Hachem.

Celebrating Life Post Transplant



Ross
Playing with my granddaughter who was born post transplant.



Ross
Vacations



Ross
I play golf twice a week and eat almost everything I want except for buffets and undercooked food

2017 Hike for Lung Health Second Wind/Respiratory Health Assoc.

Registration is now open for the annual Hike for Lung Health sponsored by the Respiratory Health Association, Chicago, Illinois as the Host Charity and by Second Wind Lung Transplant Association, Inc. as a Charity Partner.

On Sunday **September 17, 2017** walkers will gather and walk a one mile or three mile path through Lincoln Park, Chicago, IL, to raise awareness about lung disease and funds for education, and research, and Second Wind will raise funds for its Financial Assistance Program, which financially helps pay for expenses related to lung disease and/or lung transplantation, not covered by insurance.

You can join the walkers at Lincoln Park, or you can register as a "virtual walker" and participate in your home town, individually or as a group.

The registration fee is \$15 and that includes:

- Hike for Lung Health t-shirt
- Personal fundraising website
- snacks and activities at the event (if walking at Lincoln Park)

Go to www.hikeforlunghealth.org for more information on the event and to register as a walker or a virtual walker. If you can't participate as a walker, please make a donation in support of those who are walking and/or team Second Wind.



And They're Off!



Midas, the Wonder Dog,
Second Wind's shortest but most
enthusiastic Hiker!



And More Enthusiastic
Participants!

Second Wind's Newest Board Member



This is a photo of your newest Board Member, Eric Harned, pointing to a picture of himself as a baseball umpire for Life Line Ohio.



Eric participated in the annual pinwheel planting ceremony in honor of Donate Life Month in April 2017. 8,500 pinwheels were planted at the Ohio State University Wexner Medical Center, representing every organ transplant performed at Ohio State since 1967.

(Pulmonary Rehab continued from page 3)

nursing or rehab facility or discharge to home with home therapy services in the interim. Once a patient is appropriate for an outpatient program a post-transplant pulmonary rehabilitation program should be recommended and started as soon as possible. Minimizing disruptions in care and communication with healthcare personnel should be a goal for these patients.

Enrolling in rehab immediately following lung transplantation however is not without its challenges. Patients are often overwhelmed by the amount of follow-up appointments, testing, and procedures that are required in the weeks and months following transplant. The addition of a rehab program that meets several times a week may present an additional barrier to patients and their caregivers. Anxiety related to leaving the house more often, increased exposure to germs and public places, and the mere thought of exercising following transplant can often occur.

Enrolling patients in post-transplant pulmonary rehab in a time-sensitive manner allows for staff to closely monitor these patients and identify any signs of acute illness, infection or rejection. New medication regimens, increased home vital sign monitoring, and the general psychological effects of having a lung transplant can take a lot of adjusting on behalf of patients and their caregivers. The increased frequency of interactions with rehab staff makes patients more likely to communicate any difficulties they may have related to their post-transplant care. Rehab staff should be watchful for factors influencing a patient's recovery, such as cognitive deficits, nutritional challenges, financial restraints and lack of a support system or caregivers. Communicating these issues to the transplant healthcare team can result in earlier treatment, intervention, and modifications to the patient's care plan leading to overall more positive post-transplant outcomes.

Some special considerations for participation in pulmonary rehab following lung transplantation include heightened infection control measures, individualized education, breathing technique review, and more specialized exercise programming. Following transplant most patients can safely engage in an outpatient pulmonary rehab program as soon as they are discharged from the hospital. They are encouraged to wear a protective mask when out in public, including rehab, and practice good hand hygiene techniques.

Post-transplant patients can initially demonstrate breathing patterns consistent with those relied upon before their transplant. Panting, increased respiratory rate, and lack of deep diaphragmatic breathing can occur as the patient heals and has not yet fully adapted to their new level of lung functioning. This may take some initial focus on breathing retraining techniques; however the patient's breathing pattern should

*(Please see **Pulmonary Rehab** continued on page 9)*

Transplant Anniversaries

JANUARY 2017

Name	Transplant Date	Yrs
Karen Couture	01-21-96	21
Robert Klein	01-17-10	7
Anne Lovett	01-01-16	1
Paula Moscariello	01-01-94	23
Leanne Storch	01-15-14	3
Michael E. Thomas	01-16-12	5

FEBRUARY 2017

Name	Transplant Date	Yrs
Sandra Andersen	02-03-01	16
Kita Axtman	02-22-14	3
Karen Ettinger	02-01-12	5
Everett Johnson	02-14-06	11
Cheryl Keeler	02-03-05	12
Maria Loss	02-01-08	9
Peg Matthews	02-16-10	7
Ross Pope	02-10-14	3
Victoria Reid	02-08-09	8
Mark Steitz	02-16-16	1

MARCH 2017

Name	Transplant Date	Yrs
Nikki Addison	03-16-13	4
Kathryn Flynn	03-25-96	21
Eric Hansen	03-21-13	4
Paula Huffman	03--29-99	18
John Jordan	03-22-10	7
Robert K. King	03-20-08	9

APRIL 2017

Name	Transplant Date	Yrs
Gary Bland	04-07-09	8
Greg Briggs	04-30-97	20
Kathryn Bryan	04-09-16	1
Ken Carrell	04-12-08	9
Brad Messer	04-18-16	1
Tim O'Leary	04-20-16	1
Ernest Pemberton	04-04-16	1
Rick Rasmussen	04-30-05	12
Aharon Taus	04-03-07	10

(President's Notes continued from page 4)

- Plan for situations that make you want to smoke.** There are certain stressors and environments that can trigger a smoking craving. Parties, and drinking alcohol makes many smokers want a cigarette. Either excuse yourself from the room for a moment, or it may be best to avoid these situations for the first few weeks.
- Rework your routine.** Your schedule may have built in smoke breaks and cravings can hit especially hard at those times. Know when these times are and what your triggers are, then make a plan to avoid them.
- Be patient with yourself.** There is not room for self-blame or feelings of guilt when you are quitting smoking. If you do start smoking again, don't think of it as a failure. You are still learning to quit. Figure out what led to your relapse and plan on what to do differently next time.
- Keep Trying - Every smoker can quit.** It may take some time or a few practice quits, but you have the power to break this addiction. Keep trying until you find the right combination of techniques for you and you will be able to quit smoking for good.

If you need support along the way, call the toll-free Lung Help line at 1-800-LUNGUSA.

Transplant Games of America -

Transplant Games of America announced the site for 2018 Donate Life Transplant Games has been awarded to Salt Lake City, Utah. The Games will be held August 2 - 7, 2018. Time to get ready.

Have a healthy and wonderful Spring and Summer!



normalize over time.

Upper body exercises should be limited during the initial healing process, which is typically six to eight weeks or longer depending on surgical approach. Transplant recipients should follow their surgeon's recommendations for limiting such activities that could lead to chest trauma or compromise the integrity of incision sites. Light stretching and range of motion exercises using upper body muscles are typically allowable and encouraged in the early post-transplant phase. Patients are encouraged to report any incisional pain, discharge, redness or swelling to their healthcare team immediately.

Once cleared by the surgeon, transplant patients can start engaging in light intensity upper body exercise, such as arm ergometry, upper body stretching and weight lifting. These exercises should be progressed slowly and gradually using pain or discomfort as a guide. The most common exercise limitation among post-transplant patients is skeletal muscle dysfunction, specifically in regards to leg weakness and fatigue. Special focus should be given to encouraging exercises that help increase lower body muscle strength and endurance. These exercises could include but are not limited to treadmill walking with or without incline, lower body weight training, and stairs training.

Despite intensive exercise training following lung transplantation there can still be long-term limitations in skeletal muscle function and concurrently exercise performance. This specific limitation is expressed as a reduced maximal oxygen uptake (VO₂max) and early onset of muscle fatigue from lactic acidosis. The long-term use of immunosuppressant therapy among transplant recipients seems to contribute to this limitation however deconditioning and inactivity can further exacerbate it.

Eric Harned, age 54, of Columbus, Ohio received a life-saving double lung transplant at the Ohio State University Wexner Medical Center in 2014. Eric had pursued transplantation upon developing severely limiting dyspnea caused by bronchiectasis and pulmonary fibrosis. Eric said that prior to his transplant he became so short of breath that he lost the capacity to go up and down the stairs. Eric also remembers "Lifting anything that was significant like a basket full of laundry would wear me out."

Eric was only listed for three days before receiving his transplant. Eric recalls returning home on day eighteen after receiving his new lungs and states "I don't know that I had any serious fears or hesitations because it's amazing what you begin to think you can do when you aren't fighting to breathe." Eric participated in the OSU Pulmonary Rehab program three days a week for eight weeks following his transplant. Although Eric had some reservations about upper body exercises for fear of

impacting his stitches, he recalls some of the specific benefits of rehab stating, "Stretching, I thought helped a lot ... the spider crawls up the wall helped me get out of that stiff feeling."

Eric felt the aerobic exercise enhanced his endurance, describing how he went from only being able to walk about ten to twelve houses away to walking up to five miles, and eventually incorporating jogging intervals. Eric has been able to return to his passion of umpiring baseball games and does so about four times a week for about seven months out of the year. He is also looking forward to becoming a referee for basketball games, which he knows will keep him active long-term. He does all this while working full-time hours and volunteering his own personal time by speaking to students and advocating for organ donation.

Eric's take away message for anyone contemplating lung transplantation is "If you want to improve your quality of life and get back to what you were doing early in your life, the pain and physical anguish that you're going to go through in that first six months and the rehab, that is more than worth it."

Much attention should be placed on long-term exercise planning upon completion of pulmonary rehabilitation after lung transplant. Many programs offer modified Phase 3 or Maintenance programs at a reasonable fee. If this is not an option, patients should explore local facilities prior to completion of rehab so there is minimal delay in starting maintenance exercise upon "graduation" from rehab.

Different strategies can be employed to help patients feel more confident in transitioning from monitored to unmonitored, independent exercise. Teaching patients self-monitoring skills and education about proper exercise progression can ease any worry about overexerting during exercise. Patients can explore a variety of exercise modalities based on what will be available to them following their rehab program completion. Setting up an applicable, realistic, and detailed plan for maintenance exercise is vital to long-term exercise motivation, adherence, and patient confidence.

Encouraging lifetime exercise might sound overwhelming at first to lung transplant patients, however should be reiterated throughout their transplantation process. There remains a post-transplant risk of complications such as chronic rejection and decline in lung function, so maintaining optimal functional capacity is beneficial should the need for re-transplantation arise. Lung transplant recipients can participate in a variety of recreational and physical activities and enjoy the extra years their gift of life has provided them. Many patients are able to return to hobbies they once thought irretrievable and travel or attend events that they once thought impossible. Leading more fulfilling lives, transplant recipients have a unique opportunity and a "second chance" at getting the most out of life.

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

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

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.
Upcoming Programs: **Sept. 20 Rachel Janas, RD, Nutrition for Pre- and Post-Transplant Patients;**
Nov. 15 Special Presentation--Coping with the Holidays, Relaxation Techniques (Speaker TBD)
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 Washington Medical Center Seattle, WA

Meetings for 2016 (schedule pending).

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

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 / 415-353-1382

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)

(Please see Events Calendar continued on page 12)

NEW MEMBERS

Chathia Brown	Frank Carlson
Donna Chadrick	Gary Cradick
Franklin Dorthy	Leon Eisenhower
Mary L. Gallagher	Alice Gersh
James Hicks	Matthew Hill
Bernadette Mullins	Doug Powers
Mark Steitz	Amanda St. Lawrence
Michael L. Thomas	George Timmer
Michelle Wayteck	Linda Yakes

MEMBERSHIP RENEWALS

Nikki Addison	Carolyn Blaylock
Greg Briggs	Lydia Burton
Cardiothoracic & Vascular Surgical Assoc.	
Dr. Alex Charles	Betsy Cichon
Brian Conley	Karen Ettinger
Gage Georgeff	Kevin Gargon
Sheryl Helt	Patrick Henry
Gwen Herron	Paula Huffman
Everett Johnson	John Jordan
Cheryl A. Keeler	Douglas MacIntyre
Jim McClure	Cathy McGill
Peg Matthews	Brad Messer
Timothy Monahan	Paula Moscariello
Katie Moyer	Tom Nate
Tina Orlita	Michael Pazen
Cheree Peirce	Lorenzo Pope
Ross Pope	Jim Powers
Brian Puhalsky	Lori Schilling
Alan Schwenck	Shiranne Simmons
Leanne Storch	Anita Tracy
Michael E. Thomas	Craig White
Brenda Withers	David Yennior

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

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

Carolyn A. Blaylock	Leslie W. Casey
Betsy Cichon	Kimberly Gonzalez
Paula Huffman	William E. Lange
Peg Matthews	Michael Pazen
Leanne Storch	Michael E. Thomas
Anita A Tracey	Brenda Withers

Membership Fund*

P. Ross Pope	Jim Powers
--------------	------------

Financial Assistance Fund

John M Jordan	Seven Summits Therapy
---------------	-----------------------

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

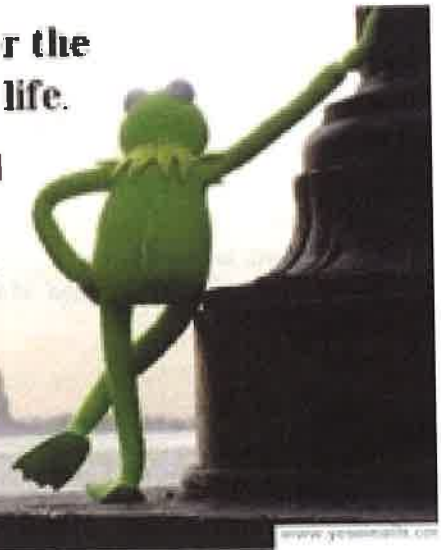
We also express our sincere thanks to all our donors who wish to remain anonymous.

In Memory Of Mary Nichols

John & Marie Curtin
Michael & Lorraine Murphy

Be thankful for the
bad things in life.

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





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

CAROL STREAM IL 601

23 JUN 2017 PM 7 L



Second Wind Lung Transplant Association, Inc.
2781 Chateau Circle
Columbus, OH 43221
RETURN SERVICE REQUESTED

19810-326010



(Events Calendar continued from page 10)

Support Groups & Events Calendar

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.