Lung Function Measurement After Lung Transplantation

By Ramsey Hachem, MD
Washington University School of Medicine
Division of Pulmonary & Critical Care

A frequent question that comes up after lung transplantation is what should my lung function be and will it ever be 100%. There are many variables that affect lung function and the percent predicted values, especially after transplantation. Spirometry is a simple and non-invasive assessment of lung function. Importantly, measurements are relatively easy to obtain and inexpensive allowing serial measurements over time. Spirometry measures the forced vital capacity (FVC), the forced expiratory volume in 1 second (FEV1), and the forced expiratory flow between 25% and 75% of forced vital capacity (FEF25%-75%).

After taking as large a breath as possible, the patient exhales forcefully and completely into the spirometer. The FVC is the volume of air that the patient can forcefully exhale. The FEV1 is the volume of air that the patient can exhale in the first second of a forced exhalation. Lastly, the FEF25%-75% is the flow rate of air between 25% and 75% of the FVC. The FVC and FEV1 are measured in liters while the FEF25%-75% is measured in liters per second. There are sophisticated equations that convert the absolute values into percent of predicted or percent of normal values based on gender, age, height, and race.

Decrements in FEV1 and FEF25%-75% without a concomitant decrement in FVC are characteristic of obstructive ventilatory defects as would typically be seen in asthma, emphysema, and bronchiolitis obliterans syndrome (BOS) after lung transplantation. On the other hand, decrements in FVC are suggestive of restrictive ventilatory defects as would be seen in pulmonary fibrosis.

In general, lung transplant clinicians rely on the absolute values of FVC, FEV1, and FEF25%-75% rather than the percent predicted values. The primary determinants of lung function (FVC and FEV1) are gender, age, height, and race. In general, men have higher lung function than women, and lung function peaks between 20 and 30 years of age. In healthy, nonsmoking adults, lung function decreases slowly with age; on average, there is a 30 milliliter per year decrement in FEV1 even in the absence of environmental pollution. This is due to slowly progressive subclinical age-related emphysema. Height is another major determinant of lung function and taller individuals have higher FVC and FEV1 measurements. Race is the last variable that affects lung function as individuals.
President’s Notes

Cheryl Keeler

President, Second Wind Lung Transplant Association, Inc.

It was an honor and privilege to be elected President of Second Wind on January 7, 2014. As I begin my first term as President, I am looking forward to working with the wonderful Board of Directors and you, the members of Second Wind, who are among the most caring, giving and unique individuals I have had the pleasure to know.

In each edition of AirWays, I will give you an update on the activities of the Board and the many projects we are working on for the benefit of the membership.

Web Site Re-Design - There are some exciting changes taking place. Second Wind is in the process of redesigning our web site: www.2ndwind.org. Our purpose in redesigning the web site is to make it more user friendly; update the medical information, as well as all of the information contained on the site; expand the ways in which you can join the association and also renew your membership on-line with the option of using a credit card; and, make the site representative of the hope and full lives that our members lead post transplant. We want the “look and feel” of the site to represent you, the membership. The Committee working on this project consists of: Chairman, Kenneth Carrell; and Committee Members Cheryl Keeler and Tom Archer. For the last several months we have been devoted to updating the information on our current site, in an effort to prepare the site for the redesign process. It may take four (4) to six (6) months to redesign the site, but we have a great beginning and we are all excited about the outcome. When the site is ready to be launched, we will notify all of the membership so that you can log on and take a look at this major project. In the meantime, there are a couple of functions on our current site that aren’t working as well as they should. We are hoping to get these functions repaired in the next month or two.

Peer Support Program - We are pleased to announce that Board Member Julie Martin has agreed to become the Coordinator of the Peer Support Program. Julie has been a valuable Board Member for many years and does a great job for the membership. Later in this edition of AirWays you will find an update article regarding the Peer Support Program.

AirWays - I am certain that many of you noticed we were unable to publish the last edition of AirWays in 2013. Our Editor has suffered some severe medical problems making it very difficult to gather all the articles and information necessary prior to sending the edition to the printer. The Board of Directors made a decision not to publish the last edition of AirWays.

(please see President’s Notes continued on page 3)
(President’s Notes continued from page 2)

2013 and to go forward with printing the first quarterly edition you are now reading. This edition of AirWays represents the first quarter of 2014. The Board wishes to thank prior Board Member and Editor Damian Neuberger and his wife Judy Neuberger for giving their invaluable assistance getting this edition to the printer. Hopefully within the next few months our Editor and Board Member Steve Schummann, we will be back to normal and we can again print AirWays on a bi-monthly basis. In order to do this, and to make our newsletter interesting to read for the membership, we need your help. We all have a story to tell. Each story is unique and individual according to your own transplant journey. Please consider submitting your story to be printed in AirWays. Your story can really help someone who is pre-transplant and facing the life changing surgery we have gone through. Thank you for your help and consideration.

Financial Assistance Program - Thanks to your generous donations supporting the Financial Assistance Program designed to provide financial assistance to our members for expenses not covered by their insurance carriers, at our January 7, 2014 Board Meeting we were able to vote to carry -over $3,130.30 from 2013 and add it to the $5,000.00 we allocated for 2014, making a total of $8,130.30 available funding for grants in 2014. So far in 2014, we have granted one application for temporary housing costs that will incur when our member gets the call for her transplant. This member called me late last night to tell me she received the call and was on her way to the hospital. When she is released from the hospital, due to your generosity, we can help with the cost of her relocating to the city where her transplant center is located. The maximum amount allocated per individual grant is $500.00; the annual amount is $500.00; and the lifetime amount for each applicant is $1,500.00. Information regarding this program for the membership can be found on our web site.

Liaison Program - We are still in need of a Liaison Coordinator. I’m certain all of us know how comforting it is when you first go to your transplant center if there is someone there to reach out to you and tells you about an organization that is dedicated to helping them in any way that they can. That person is Second Wind’s Liaison for that particular Center. If you are interested in becoming a Liaison at your Center (if they don’t have one) or if you are interested in becoming the Liaison Coordinator for this Program, please email me at keelerc768@aol.com I would be glad to discuss this very important program with you.

Board Members Late last year we sent out a “Board Member email” seeking candidates who desired to share their talent by serving on the Board. Unfortunately, we did not receive any applications to become a Board Member. Currently, we have five (5) openings for Board Members. There are many projects that aren’t listed in this President’s Note that the Board continues to work on. The Board works to identify and implement new member services and maintain current services such as our newsletter, Listserv, Message Board, Peer Support Program and website. Directors also work to increase membership and funding for the Association. If you are interested in becoming a Board Member, please contact me at keelerc768@aol.com or call our help line at 1-888-855-0463.

Again, I look forward to the upcoming year and to working with and for all of you!

Lung Function continued from page 1)

of different races may have different trunk to height ratios.

After lung transplantation, there are numerous factors that influence peak lung function. Obviously, bilateral lung recipients will have higher lung function than single lung recipients. But, there are important donor-related factors that influence lung function. Donor height is the most influential variable; recipients of lungs from taller donors will generally have higher peak lung function. Donor height is an important factor in donor selection for an individual recipient. Obviously, recipient height will influence this selection. In addition, the recipient’s underlying lung disease will determine his or her chest cavity size. For example, emphysema, cystic fibrosis, and obstructive lung diseases in general are associated with hyperinflation of the lungs as a result of trapped gas at the end of exhalation. Over time, this results in hyperinflation of the chest cavity size. In contrast, pulmonary fibrosis progressively reduces lung volumes and there is a concomitant decrease in chest cavity size over time. As a result, patients with obstructive lung diseases can generally accept lungs from donors who are taller than they are while those with restrictive lung diseases such as pulmonary fibrosis generally have to have donors who are shorter than they are, and this will influence peak lung function after transplant. For example, some patients with emphysema may have peak FVC and FEV1 measurements over 100%, and sometimes over 130%, of their predicted values after transplantation, while some patients with pulmonary fibrosis may have peak FVC and FEV1 measurements 70-75% of their predicted values. Nonetheless, although their lung function is lower than predicted, these patients usually have no functional or clinically significant limitations.

In addition, complications early after transplantation may affect peak lung function. Recipients who develop severe primary graft dysfunction (PGD) tend to have lower maximal lung function after transplantation because of...
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.

Give Life A Second Chance

For additional product details and to purchase T-Shirts, Caps, Totes, the NEW Crew Pullover Sweatshirts, and the NEW Zip-up Hoodie Sweatshirts on-line go to: http://www.2ndwind.org/store/index.html. Click on “order form” under Payment Options.

Second Wind Store Items

Full Outfit Front View Tote, T-Shirt, and Cap
Cap and T-Shirt front logo
Back of T-Shirt Logo
Julie Martin
Damian and Judy Neuberger on their 50th wedding anniversary. Damian received his bilateral lung transplant on Oct. 19, 1997 and his anonymous living kidney transplant on Oct. 19, 2011.
In Honor Of

Jack Austin

Dear Fellow Second Wind Members:

It is with deep regret and sadness that I must report the passing of one of our Board Members; Jack Austin. There are those in the transplant community who are dedicated to sharing and helping others as they face the challenges, and yes the joys of life, after receiving a lifesaving lung transplant. Jack was one of those people.

Jack first joined Second Wind on February 18, 2007. Sixteen months later on June 16, 2008 he received a bilateral lung transplant at Shands Transplant Center, University of Florida in Gainesville, Florida. Prior to his transplant, Jack suffered from Chronic Obstructive Pulmonary Disease. After his transplant, Jack received a second chance, a “Second Wind.”

Almost immediately Jack began sharing his experiences with others on Second Wind’s Message Board and on Second Wind’s Internet Support Group. I have learned from Jack’s wife, Sandy, they regularly attended the weekly Shands Adult Lung Transplant Support meetings where Jack would always “give his speech about Second Wind, give out his cards, phone number and information to all who would take one and proudly tell them he would do it all over again when asked.” I was not a bit surprised.

Jack served as Second Wind’s Liaison at Shands. He would talk with new transplant patients, introduce them to Second Wind and let them know they weren’t on this journey alone. Jack also served as Second Wind’s statutory business Agent in the state of Florida and joined the Board of Directors in late 2012. Prior to joining the Board, Jack was one of the first Second Wind members to contact me and volunteer to be a Peer Support Program Mentor for the newly created Peer Support Program.

Jack and his wife Sandy were married for fifty-three (53) years; had two sons, five granddaughters and one great-grandson. Sandy shared with us that they felt truly blessed and that she was doubly blessed to have such a good, kind, loving husband.

Jack Austin was a good, kind and caring man to all in the transplant community. We at Second Wind were truly 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. Jack died from chronic rejection on December 26, 2013 and we all will miss him very much.

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

#### December 2013

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<tr>
<th>Name</th>
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<tr>
<td>Grace Bachman</td>
<td>12-3-2005</td>
<td>8</td>
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<td>Gage Georgeff</td>
<td>12-14-2009</td>
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<td>Fred Walker</td>
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<td>Betsy Cichon</td>
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<td>Dave Griggs</td>
<td>12-27-2010</td>
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#### January 2014

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<tr>
<td>Paula Moscariello</td>
<td>1-1-1994</td>
<td>20</td>
</tr>
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<td>John McNamara</td>
<td>1-1-2006</td>
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<td>Dennis Wright</td>
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<td>Karen Jacobson</td>
<td>1-12-2007</td>
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<td>Michael Thomas</td>
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<td>Robert Klein</td>
<td>1-17-2010</td>
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<td>Thomas Barbour</td>
<td>1-18-2011</td>
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<td>Karen Couture</td>
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<td>Cathie Weir</td>
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#### February 2014

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<td>Karen Ettinger</td>
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<td>Sharon Barlow</td>
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<td>Sandra Andersen</td>
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<td>Cheryl Keeler</td>
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<td>Starla Sage</td>
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<td>Martha C. Becker</td>
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<td>Peg Matthews</td>
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<td>Stacy T. Veasey</td>
<td>3-14-2005</td>
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<td>Donald Poole</td>
<td>3-14-2012</td>
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<tr>
<td>Nikki Addison</td>
<td>3-16-2013</td>
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<td>Robert Kevin King</td>
<td>3-20-2008</td>
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<td>Angus McDonald</td>
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<td>John Jordan</td>
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<td>Darcy Shaw</td>
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<td>Kathryn M. Flynn</td>
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<tr>
<td>Paula Huffman</td>
<td>3-29-1999</td>
<td>15</td>
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<tr>
<td>Sarah Andrews</td>
<td>3-29-2012</td>
<td>2</td>
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**Congratulations to all who celebrate another milestone!**

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**Second Wind Peer Support Program Update**

Cheryl Keeler

President, Second Wind Lung Transplant Association, Inc.

Bilateral Lung Transplant, Cleveland Clinic, 2-3-05

**In February 2008, Second Wind Lung Transplant Association announced the creation of the Second Wind Peer Support Program. This program was developed for lung transplant patients; pre and post transplant; those investigating the possibility of lung transplantation; and, for Caregivers of lung transplant patients.**

The program is designed to provide support and education for patients and/or caregivers from a peer perspective through one-on-one communication through emails, telephone calls, mail, or visits. Prior to the announcement and since, Second Wind has sought out members who will act as Peer Support Team Members (mentors) and share their own individualized personal account of their transplant process and continued recovery. Our Team Members are people we trust to instill the confidence and encouragement required to move forward through the transplant process.

*(Please see Peer Support continued on page 7)*
We are very pleased to announce that Second Wind has a new Peer Support Program Coordinator. Board Member Julie Martin has taken on this responsibility and we are very excited for the months ahead. Julie is dedicated to improving the quality of life for lung transplant recipients and pre-transplant patients by providing the type of guidance and education that is achieved through the Peer Support Program. Please remember that Peer Support Team Members do not give medical advice; those questions must be directed to your physician and transplant team members.

Just as a short reminder as to how the program works, the Peer Support Program will be facilitated by emailing Julie Martin at JAM1748@sbcglobal.net, contacting Second Wind via the Email Support Group, or through the Second Wind toll-free help line (888-855-9463). If you are interested in speaking with a Peer Support Team Member (mentor), simply email Julie. After obtaining some necessary information, we will provide you with a list of up to five Peer Support Team Members (mentors), including their transplant center, diagnosis, date of transplant and email address. You are free to contact all of them or as many as you wish. Rooted in their transplant experience, the Peer Support Team Member answers questions related to lung transplantation and shares their own experience. If you are interested in becoming a Peer Support Team Member, please contact Julie at the email address listed above, or contact President of Second Wind, Cheryl Keeler at keelerc768@aol.com.

Currently, we have fourteen (14) Peer Support Team Members (Mentors). They represent seven different transplant centers and live in nine different states. When asked to describe why they felt they would be a successful member of the Peer Support Team, here are a few of the answers:

“I remember how important it was to me to talk with other transplant patients before, during and after transplant. I would be honored to help others through this wonderful, intense time. I haven’t forgotten how crazy it sometimes felt, especially with my children and living away from home before, during and after transplant.”

“The period of time from being listed for a transplant and the “call” was the most fearful time of my life and being so ill at the same time is quite a combination. I know how people feel.”

“I would like to give something back in return for my second chance and to fill in some blanks for others, that maybe could ease some concerns or allay some fears that I know we all experience.”

We have received numerous calls from patients requesting that a “mentor” get in touch with them. Sometimes the participant only has a few questions they want answered. Other times continued communication takes place. Even if you only have a few questions you want to ask another transplant patient, it is reassuring to know you have a contact with another transplant patient you can reach out to at any time. Here are samples of comments we have received from participants:

“This is an excellent idea. I’ve needed many questions answered and I’m not even anywhere near being listed yet. Thanks for a great plan.”

“Talking to me helped me decide to go through with this. I would have done it regardless, but you took away those little fears I had – you know those little “what ifs.” I can’t thank you enough.”

“I’m very nervous and scared but I am ready to get it done and start the healing process. Thank you for talking with me and answering my questions.”

“I’m sure questions will pop up as the process moves along. I won’t hesitate to contact the people you listed. Thank you.”

Lung transplantation can be a renewal of one’s life, but it is also challenging and life changing. There is no need to face the challenges alone. We at Second Wind hope that you will reach out to those who have walked the road you are now walking, so that we may help each other along this very different path in life. To request that a member of the Peer Support Team contact you, please contact us by emailing Julie Martin at JAM1748@sbcglobal.net or Cheryl Keeler at keelerc768@aol.com. For more information about Second Wind Lung Transplant Association, please visit our website at: www.2ndwind.org.

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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

St. John Medical Center
26908 Detroit Rd. Second Floor Conference Room
Westlake, Oh 44145A Second Chance Support Group for pre, post, and caregiversSecond Monday of the month 6-8pm
Contact Lynn Gorton
Lynn.Gorton@csauh.com Phone: 440.250.2042

(Please see Events Calendar continued on page 10)

We Remember

Jack Austin
Orange Park, FL
Bilateral Lung Transplant
June 26, 2008
Shands Transplant Center
Died: Dec. 26, 2013

Christopher Badger
Morrisonville, NY
Single Lung Transplant
Feb. 9, 2008
Brigham & Women’s Hospital
Died: Jan. 7, 2014

Dock Foster, III
Aurora, CO
Single Lung Transplant
Jan. 31, 2009
U. of Colorado Health Center
Died: July 9, 2013

William (Bill) Tamisiea
Yankton, SD
Bilateral Lung Transplant
April 7, 2008
Mayo Clinic
Died: April 27, 2013

Mary Mercatante
Died: Aug. 28, 2013

At the going down of the sun and in the morning
We shall remember them!
New Members and Membership Renewals
September 2013 — December 2014

NEW MEMBERS

Bernadette Boyd Rick Kamm
Charlene MacEachran Daniel Patterson
Cheree Peirce Ross Pope
Richard Williams

(Four new members have requested confidential memberships)

RENEWALS

Sandra Andersen Patricia Ashbridge
Carolyn Aspegren Sandy Austin
Martha C. Becker Greg Briggs
David Courtney Robert E. Courtney
Karen Couture Mary Ann Cruse
Bev Donelson Patrick Dooley
Lisa Fry Gage Georgeff
Robert Glim Donald Gwynne
Mary Hardy Robert Hutcherson
Jane Kurz Frances Lambert
Scott Larrimer Carrol Litwin
Maria Loss James Lyons
Loyola University Medical Center c/o Dr. Dilling
Julie Martin Douglas MacIntyre
Garry Nichols John McHale
Irene Overton Michelle O’Guinn
Starla Sage Brian Puhalsky
Alan Schwenck Lori Schilling
Marilyn Sundt Darcy Shaw
Karen Swenson Mark Swartz
Anita Tracy John Swihart
Fred Walker Stacy T. Veasey
Jim Withers Cynthia White

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

Greg Briggs Frances Lambert
Scott Larrimer Garry Nichols
Michael Pazen Frederick E. Walker
Loren Gerhard & Cathy Cuenin Frank Shields
Debbie Guthrie Angus McDonald
Beth Mitchell Angela Hartman
Richard Scenna

Donations for Financial Assistance Fund

Garry Nichols Michael Pazen
Michael E. Thomas Stacy T. Veasey

Donations for Membership Fund*

John McHale Garry Nichols
Michael Pazen Karen E. Swenson

* 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.

Second Wind Could Use Your Help

The Second Wind Financial Assistance Program is growing faster than we can keep up with the many requests. The Board has set a budgetary limit to what we are able to extend in grants each year. We would very much like to increase our level of aid for 2014, but we need donations to the Financial Assistance Fund to make that possible. Please consider a generous gift to that fund and look into the possibility of matching donations from your workplace as we highlighted in the March-April 2013 issue. Thank you for your consideration.
Support Groups & Events Calendar

University of Washington Medical Center
Seattle, WA  Meetings for 2013

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

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

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
Every other month, Please call or email for exact dates.
DCAM Building Rm 1005, 5758 S. Maryland Avenue
Chicago, IL 60637
Only pre & post-transplant patients & support person(s) followed at UCMC
Contact: Danley Kohn, LCSW
Danley.kohn@uchospitals.edu or call 773-834-8076

University of California San Francisco
Lung Transplant Support Group, Third Thursday of every month, 1-3 pm, Room 1015.
505 Parnassus Ave., San Francisco, CA  94143
Contact: Avry Todd, MSW, 415 353-1098
Apryl.Todd@ucsfmedctr.org