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### 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

## Happy Anniversary Second Wind Lung Transplant Assoc., Inc.

### President's Notes Cheryl Keeler

On November 6, 2015 Second Wind Lung Transplant Association, Inc. celebrated its 20<sup>th</sup> anniversary. On November 6, 1995 Second Wind was incorporated in the State of Florida. Second Wind was founded by a small group of dedicated individuals who sought to provide information about lung transplantation and they adopted the slogan "Support through Service."

Since then, through the dedication of numerous volunteers and Board Members, the organization has remained faithful to its original Mission:



*To improve the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concerns, and their families, caregivers and friends by providing support, advocacy, education, information and guidance through a spirit of service, adding years to their lives and life to their years.*

Second Wind's membership has reached its cumulative total of over 4600 from the United States and thirty-four (34) foreign countries.

Second Wind's Mission has been accomplished by the following methods:

- ◆ Publishing the *AirWays* Newsletter
- ◆ Maintaining and recently re-designing an Internet Web Site: [2ndwind.org](http://2ndwind.org)
- ◆ Maintaining an Email Support Group
- ◆ Maintaining a Web Message Board
- ◆ Maintaining a Facebook page: Fans of Second Wind Lung Transplant
- ◆ Offering a Financial Assistance Program
- ◆ Offering a Peer Support Program
- ◆ Providing information and support through a toll-free help line: (1-888-855-9463)

In order to meet our goals and provide services, Second Wind relies primarily on

*(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:

schumann10.ss@gmail.com

Send hardcopy submissions to the editor:

Steve Schumann

1020 S. Gull Court

Palatine, IL 60067

For more information contact:

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 continued from page 1*)

membership dues and the generosity of caring individuals through donations. We also work with corporations to provide additional financial support through grants and employer matching donations.

As we go forward, we are continually humbled by those who volunteer to help with the various programs, and thankful for all who support our efforts in this much needed endeavor. We believe that no one needs to walk the transplant road alone.

We have included in this edition of *AirWays* several members' stories from our long-term members, with long post-transplant survival. We hope that you enjoy reading about their Transplant journeys and find hope and peace in their words.

The Board of Second Wind wishes all of you and your families Happy Hanukkah, Merry Christmas and a very Happy New Year!



## Truly Blessed and Breathing

Karen Couture

1996 Bilateral Lung Transplant Recipient  
Shands Hospital in Gainesville, Florida

I started having shortness of breath in the early 1990s, but I never sought treatment for it. At the time I was a very athletic and busy person working two jobs. So, why was I having such a hard time climbing a few flights of stairs? After all, I had scaled mountains before. It was stress, right? But, I was proved wrong after I was hospitalized with multiple lung collapses in 1992. I was finally diagnosed with lymphangioleiomyomatosis (LAM), a rare lung disease. Since LAM only occurs in women, I was given hormonal treatments in the hopes of slowing the progression of the disease. And, if that didn't work, they'd have to try a lung transplant!

Over the next couple of years my lung function continued to decline until I was on oxygen and needed a wheelchair. I also needed a transplant. I was initially listed at Mass General Hospital in Boston in 1994. But, after doing some research, I realized that I had been referred too late in the process in order to survive the wait for lungs up North. (Back then, your

(Please see *Blessed and Breathing* continued on page 3)

*(Blessed and Breathing continued from Page 3)*

medical status was never calculated into your place on the list; you just had to wait your turn in line no matter what your medical condition was.) So I searched the country to find an area that had a shorter regional waiting list in addition to a center willing to transplant me. Eventually, I transferred to Shands Hospital in Gainesville, Florida.

Fortunately, I received a bilateral lung transplant on January 21, 1996, only four months after I moved to Florida. My FEV-1 peaked at 122% within a year and my quality of life was greatly improved! So I decided to go to the World Transplant Games in Sydney, Australia in 1997. The Transplant Games are an Olympic-styled event where transplant recipients

from all over the world compete in running, swimming and biking, etc. I swam in the butterfly stroke and the relay race, but never medaled. I didn't care. I was alive and could breath again.



A couple of years later, I decided to put my background in publishing to good use and write a book. But I decided I didn't want to write about my transplant experience

since there were already many good books out on the subject. Instead, I wrote a more practical book that would share what I had learnt about the process of getting on the list, the wait, the eventual surgery, and beyond. That book became "The Lung Transplantation Handbook," which I self-published in 2000.

During this time, I also went back to work. First, I got a job as a full-time web site designer, but the stress of the transplant and the work schedule were too much for me and I had to quit. I then went back to work part-time as a photographer's assistant, which I did for a number of years. But that job didn't fulfill me, so I went back to school and got certified as a massage therapist. I really loved doing that work because it gave me a chance to help others. That was the most important thing to me since I had received so much through the transplant and wanted to give back.

As the years have gone by I've had many hospitalizations. I've been sick with aspergillus, andenovirus, parainfluenza, RSV (respiratory syncytial virus), CMV (cytomegalovirus), and C-difficile, among others. Each time I had a new infection, my lung function would decline. By 2014, my lung function had dropped to a low of 33%. So, I proposed to my transplant pulmonologist doing photopheresis, an experimental treatment, in the hope that it would reverse or at least slow down my lung function decline.

Initially, I was supposed to receive 24 treatments, but I had to stop mid-way through because I developed pains in my abdomen, which required hospitalization. There

it was discovered that I had developed PTLTD or post-transplant lymphoproliferative disorder. PTLTD is a type of cancer that can develop in transplant recipients due to their immunosuppressive drugs.

So, I started chemotherapy treatments right away. These lasted for several grueling months. In November of 2014 I was pronounced, "Cured!" But that happy state of affairs didn't last long. I began having abdominal pains again in January of 2015, and by March I was diagnosed with PTLTD again. Unfortunately, I had to go through even more chemotherapy. In June I finished the necessary treatments and as of December, I am happy to report I am in remission!

It has been almost 20 years since my bilateral lung transplant! When I tell people about my story, they are usually either amazed or dismayed to learn how much I've been through. But, I often tell them that having a rare lung disease and having a lung transplant have been one of the greatest BLESSINGS in my life. I was fortunate enough to have learnt at a very young age what is really important in life, which is loving one another. It has also opened my eyes to the suffering of others and made me a much more compassionate person. I am also a much stronger person than before having gone through all the trials and tribulations that transplantation can bring. All in all, it has not always been easy, but I would not trade this life for any other.

In closing, I'd like to thank my husband, Mike, and my family for taking care of me and for sticking with me through all the tough times. I'd also like to thank my transplant doctors and nurses whose care and expertise have carried me through all these many years. And, last, but not least, I'd like to thank my donor family, The Richards, for their sacrifice and for helping to make the last 20 years of my life possible. Words can never express how thankful I am. I remain truly blessed and still breathing!



## **Kathryn Flynn's Story**

**Bilateral Lung Transplant March, 1996  
Duke University Medical Center**

**G**rowing up with a father who smoked, it is not too surprising that I took up smoking at an early age. At 13, I wrote down the one to two cigarettes per day that I smoked in a diary, but I don't know when it turned into one pack and then two packs a day. I had frequent bouts of bronchitis and occasional pneumonia—this was normal for me. It wasn't until I wanted to get pregnant, at age 26, that I quit smoking. I fully expected to be able to pursue a more active lifestyle as a result of quitting, but physical activity never did get easier. The dry smoker's hack did not go away

*(Please see Kathryn Flynn continued on page 4)*

My life and my husband's life changed dramatically at that appointment. I was put through test after test in the hospital, given a lung lobectomy, and was sent home on oxygen 24/7 with nothing but a sheet of suggested exercises and a prognosis of 2-8 years to live without a lung transplant. My primary care doctor brought papers about Toronto's lung transplant program to my home. A compassionate oxygen delivery man told me about Duke's Center for Living, a pulmonary rehabilitation program for patients like me. This program taught me how to exercise, even with limitations, and gave me the confidence to return to work in an active capacity as a laboratory research technician.



on oxygen was daunting. I still pray to this day for that baby—that he was given a very special home. My daughter, Sarah, is a happy, healthy, young adult and has always been a source of joy and hope.

I have had the unique privilege of being able to live my life since transplant as if I truly believed (and I did at times) that each day could be my last. I did not rush back into work but enjoyed my family, volunteering at my daughter's school, volunteering for Carolina Donor Service, volunteering for Sec-

In 2013, I lost my soulmate and my husband, Richard Merritt. I celebrated my 18<sup>th</sup> and 19<sup>th</sup> transplant anniversaries without him by my side. Here's to you, Rick.

## by Matt Wood

Christopher Wigfield, MD, Surgical Director of the lung transplant program at the University of Chicago Medicine, demonstrates the ex vivo lung perfusion system during a trial run at the Center for Care and Discovery.

To overcome these challenges, the University of Chicago Medicine has become the first hospital in Illinois to use a new system called “ex vivo lung perfusion (EVLP)” to prepare donor lungs for transplant. The procedure allows physicians to assess the viability of donor lungs that don’t meet the typical criteria for transplant--lungs that doctors may not have considered using in the past. More than 50 percent of lungs evaluated with the system are ultimately deemed suitable for transplant, which has increased the number of available donor lungs significantly.

“This really heralds a new era in lung transplantation, as we will eventually have additional lungs for transplant candidates, and have the opportunity to rule out truly unsuitable grafts and reduce the risk of life threatening complications from marginal quality donor lungs” said Christopher Wigfield, MD, Surgical  
(Please see **New Technology** continued on Page 7)

# Paula Moscariello's Story

Transplant Date Jan. 1, 1994  
Massachusetts General Hospital

I was given another chance at life way back in 1994. I call it the prehistoric times because there were no cell phones. We were given beepers while waiting for our lungs. After waiting just under 3 years on the lung transplant list, oxygen tank in tow, I received a double lung transplant on April 24th, 1994. (My disease is Cystic Fibrosis).



The first year was terrible. Right away my digestion shut down, I was diagnosed with prednisone driven diabetes and 6 weeks after my transplant I was diagnosed with Lymphoma in my lungs. My doctors tried taking me off all antirejection drugs but I went into rejection. I was put on a lower dose of cyclosporine, along with an I.V. drug called IGG which I would get every three months for a long time. Within three months the cancer was gone.

I would say it took about a year to start feeling like myself because of all the drugs, stress, and running to doctor's appointments.

I never went back to a formal job but I did a lot of volunteer work, traveled, and took up the game of golf. I was involved in running a Pitch and Putt ladies golf league for several years and played in the league for 18 years.

About 4 years ago I had terrible chest and back pain. Nothing was being done so I requested to see a physical therapist and she found my whole breathing pattern was off. This was followed by seeing a chiropractor who found I weighed 13 more pounds on my right side than my left. Then the rehab began - icing, walking, deep breathing. Meanwhile, I left my transplant hospital and went across town to another transplant hospital. I have been very pleased with my care there. My move was so successful it gave me the courage to change all, yes, all of my doctors. So now I have all doctors I love. I now play pickleball a few times a week, I do yoga daily, I've taken agility training and Rally training with my dog, but settled on making homemade agility courses in my backyard in order to have more time and energy for playing and practicing pickleball.

## MY TOOLS

- My fabulous Husband
- Peggy Cappy's yoga for pain and backs
- My Chiropractor (keeps my back loose).
- I dabble in meditation and visualization.
- Role Model book by Jill Miller or her You Tube videos (shows how to release fascia or scar tissue with balls).
- Diabetes Organization book by Susan Weiner and Leslie Josel (Not just for diabetics)
- Foodmap, gluten free, dairy free. I do a combination of all three.
- Life Coach—She's taught me to live my life, not just to go through the motions.
  - You always have choices.
  - Sometimes you have to say "no" to good things.
  - Listen to your gut.
  - You're a whole person like everyone else, transplant is just a small part of you.
  - Don't let other people or statistics tell your story, it's your story.



## Second Wind Volunteers

Cheryl A. Keeler, President

Over the last few years, Second Wind has been blessed with the help of invaluable volunteers. The Board of Directors has always been composed of volunteers. However, I want to address a few of our volunteers who are not Board Members.

During the past few years, I personally have had six hospital stays. Over those extended periods of time and during my recovery, a dear friend and past Board Member, Mary Hardy, volunteered to handle Second Wind's database. These duties included all data input, recording all membership renewals, emailing new members regarding benefits of membership, making certain that new member packets were requested, and requesting that receipts and thank you letters be mailed for donations made to Second Wind. Without these functions being completed, Second Wind would have come to a screeching halt. We rely solely on the database for

*(Please see **Volunteers** continued on page 6)*



information about our membership including addresses for mailing *AirWays*, members celebrating transplant anniversaries and new and renewal memberships. Thank you Mary for helping out every time we needed you.

Another volunteer we want to thank and acknowledge is Tina Giampapa Orlita. Tina is also a prior Board Member. When a new member joins Second Wind, Tina is notified and she prepares and mails out a "new member packet." This packet includes a welcome letter from Second Wind, a listing of all of the benefits of membership and their first copy of *AirWays*. Since this is their first contact by mail with Second Wind, it is very important that these packets arrive in a timely manner. Tina does an excellent job for Second Wind and thank you Tina from the Board of Directors.

One other volunteer who stepped in when we needed him the most was Dr. Damian Neuberger. Damian is a long time member of Second Wind and served for many, many years as a Board Member, Officer and Editor of *AirWays*. Last year when our current 1<sup>st</sup> Vice President and Editor, Steve Schumann was dealing with several medical issues, I didn't hesitate to contact Damian to see if he could help us get *AirWays* to print. Damian didn't hesitate to help. He met with Steve and started work for the layout for that edition of *AirWays*. When Steve was able to return to the task he stepped in and picked up where Damian had left off and was able to bring that edition to press. In 2011 when he was passing over the editorial reins to Steve, he (and his wife Judy) provided invaluable help to Steve, acting as a mentor to learn the ropes of a very complex software program. For his willing service we thank you so much.

Last among our volunteers is our Web Master, Dan Cihon. Dan has been our Web Master for more than ten years. Professionally, he is an Information Technology Manager for a company in St. Louis, MO and works full-time in his area of expertise. As many of you know, Second Wind recently launched our redesigned web site. Dan was instrumental in getting this project moving forward and making the necessary changes that allowed the Design Committee to create a more user friendly web site for all in the lung transplant community to enjoy. As the Committee was reviewing our old web site, we would email Dan to determine if we could change an aspect of the page, and also to ask him to make the change on our current site. We spent months sending emails to Dan to make changes on our old site, so when we submitted it

to the design company to create our new site, they had a product they could work from.

When the redesign was completed, Dan joined the Design Committee on a telephone conference workshop to go through the language of the new site and the design elements. I can tell you without a doubt, Dan is the only person on the training conference call who could follow the directions of the designer and knew what he was talking about. Now that the new web site is up and



Dan Cihon

running, Dan keeps it that way. Our data base interacts with our web site, and Dan handles the coordination of these systems. The Board of Directors is so thankful and appreciative of the work that Dan does for Second Wind. Whenever there is a problem or a need on the web site, Dan takes care of it. This method of communicating, with not only our membership

but the transplant community, is an essential means of providing services and fulfilling Second Wind's Mission. Dan keeps this avenue open for us and we recognize the excellent quality of his work. Thank you Dan.

All organizations, profit and nonprofit, are made stronger by their employees and/or volunteers. It is the sum of all of the parts that matters. Here at Second Wind we are humbled by the many volunteers, both Board Members and non-Board Members, who over the years have helped to make Second Wind successful in accomplishing our Mission to improve the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concerns and their families, caregivers and friends by providing support, advocacy, education, information and guidance through a spirit of service, adding years to their lives and life to their years.

Thank you to all of our volunteers. If you would like to share your talents and volunteer to help Second Wind, please contact me at [keeler768@aol.com](mailto:keeler768@aol.com) or call our toll-free Help Line at: 1-888-855-9463.

# IPF Runs in Our Family?

Ross Pope

Second Wind Board Member

In 2005 my sister, Susan Sweeney was diagnosed with IPF. The doctor told her to get her things in order because the average life expectancy after diagnosis was 3 years or less. My sister was about 52 years old at the time. Well, a concerned doctor offered her the opportunity to be involved with a clinical study of Pirfenidone. She agreed and we are convinced that it extended her life by at least 7 years.

While she was involved in the clinical trial, I was starting to notice an increased need to clear my throat and I was losing some stamina, so I decided to go to a pulmonologist to get checked out. They said my symptoms were not positive that I had the same disease, but they had to perform a lung biopsy before being 100% positive. I didn't want to go through a biopsy but I did and the doctor called and said for certain I had IPF. He also told me to get my affairs in order because I had 3 years or less to live and there was no cure. I asked about Pirfenidone and he told me the trial was closed and the only possible hope was a lung transplant. He referred me to Cleveland Clinic. My sister's decline was slow over the 7 years she was on Pirfenidone, but mine was drastic as I received only supportive treatment. Within a year I was on oxygen and slipping down the slippery slope quickly.

Cleveland Clinic monitored my decline and placed me on the transplant list in December 2013...I didn't realize how sick I was but Cleveland Clinic did. I was transplanted in February 2014 with a single lung. I was out of the hospital in 8 days and back in for a few days the next week for a blood clot, but my recovery steadily progressed. It's been almost two years and I feel great! I have been able to go on a cruise, jet skiing, hunting, climbing mountains, playing golf, trying out a hoverboard and not restricted to much of anything.

My sister, Susan, was on the decline after 7 years on an unapproved FDA drug. Again, her Drs. initiated finding a hospital that would transplant her because in the middle of all of this she had breast cancer. When doing the work-up, her PET scan came up clean so she was cleared for a double lung transplant that took place at UTSW in Dallas Nov. 2014. She lives in KC but UTSW was the only center that would accept the risk due to her bout with cancer. It's been over a year for her and almost 2 years for me and we are both thankful for generous donors and great doctors and staff to help us through the miracle of a lung transplant.

If you are wondering if IPF can be hereditary, I think the answer is "yes" since our mother died of IPF at age 51 in 1974 (before they knew much about IPF). My older brother has recently been diagnosed with IPF and his lung capacity is about 50%. His future may include a transplant also, but for

now he just started on Pirfenidone, (now called Esbriet since approved by the FDA). Our family is here to make a case that the prognosis of five years longevity is the average life expectancy post transplant is increasing.

I have accepted a position on the Board of Second Wind because I want to give back to those going through the challenges of breathing and at times not knowing where to turn for help and support. May God bless you all as He has blessed us through the prayers of other and the miracles of modern medicine.



Ross Pope and Susan Sweeney



*(New Technology continued from Page 4)*

Director of the lung transplant program at the University of Chicago Medicine.

During the EVLP process, physicians connect donor lungs to a circulation system that runs a solution through the blood vessels. This gently warms up the lungs after transport and establishes normal tissue flow. Physicians can then re-ventilate the lungs in a gradual, controlled manner, expanding them more deliberately compared to when they're transplanted directly in the recipient. This decreases the risk of damaging the lungs and allows detailed assessment to ensure more successful transplants.

The University of Chicago joins 15 other sites in the United States currently using the XVIVO Perfusion System (XPS™), manufactured by XVIVO Perfusion AB, based in Goteborg, Sweden. A trial in Canada and subsequent FDA approval has paved the way for use in the US.

Currently, only one out of five donors who give organs of any kind provide suitable lungs, placing an even greater demand on the organ donation system. Nearly 1,700 people in the United States are already on the waiting list for lung transplants.

"Despite this scarcity of acceptable donor lungs, more lung transplants are performed every year, aggravating the situation

*(Please see New Technology continued on Page 11)*



# 20 year Celebration of Support and Education in the Lung Transplant Community



Editor Steve Schumann  
enjoying life 5 years  
post transplant in an  
Alaskan rain forest 2012

Hike for Lung Health Fundraiser organized by the Respiratory Health Association of Chicago was held in Lincoln Park, Chicago in September 2015. Second Wind was one of the Charity Partners for this activity. Pictured are the team captains of the walkers who raised the pledges for the event. Second Wind was represented by our own Frank Shields, 2nd from right. The money raised by this walk will be used by RHA to help promote healthy lungs and fight lung disease through research, advocacy and education.

Photo courtesy of Respiratory Health Association.



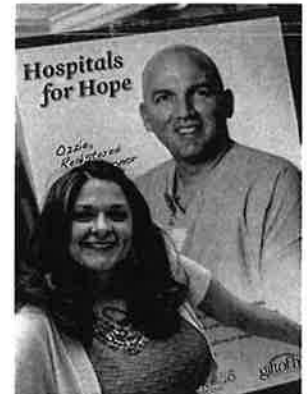




The University of Chicago Medical Center celebrated their first ever Lung Transplant Recipient Reunion at the Medical center in April 2015.

The reunion was a huge success with over 100 people attending, including recipients and family members. Medical Center nurses and doctors, and Gift of Hope representatives.

The Master of Ceremonies was Jamie Bucio, Thoracic Organ Procurement coordinator (pictured below). She did a tremendous job managing all of the festivities including selecting speakers with their inspiring stories



Steve Schumann (again!) with Jorge Del Gado, returning the oxygen supplies that kept me going while I waited for my lungs. This day was a major landmark as I was returning that equipment because my new lung worked so well! Jorge, with whom I had grown quite attached, was as moved as I was because the usual case was that he usually picked up these supplies after a patient had died. It was also the first time that a patient actually helped load the supplies back in his truck, a chore I was very delighted to help with!

## Introducing New Board Member Tom Nate

The Board of Directors for Second Wind Lung Transplant Association, Inc. is pleased to announce its newest Board Member, Mr. Thomas Nate of Bandera, Texas. Mr. Nate was elected to the Association's Board of Directors at the first annual meeting of the Board on January 5, 2016.

Tom received a bilateral lung transplant at Barnes Jewish Hospital in St. Louis, MO, on May 3, 2007 after being diagnosed with Kartagener Syndrome and Bronchiectasis. Approximately eight months later he was diagnosed with chronic rejection. Tom received a second bilateral lung transplant, again at Barnes Jewish Hospital, on September 20, 2010.



Tom sought election to the Board of Directors for the following reasons:

*"I am interested in serving Second Wind and the lung transplant community and am applying for one of the vacant positions on the Board of Second Wind Lung Transplant Association. Since my first bilateral lung transplant*

*and recovery, I have actively sought opportunities to mentor and support other lung transplant patients, both pre and post-transplant. Having been a participant in the Barnes Jewish Hospital Transplant Mentor training, I have stayed involved each year including continuing to mentor transplant patients while I was in chronic rejection and even through the wait for my second bilateral lung transplant. I have been blessed to be called upon to mentor long distance patients, like myself to help them overcome their fears of moving toward taking the transplant journey. I have also spoken at churches, bible study groups and respiratory therapists groups sharing my story and experiences with them. I have been active with Donate Life Texas to spread the word on the importance of organ donation and sign up new donors. I am currently five years post on my second bilateral lung transplant having just completed my 5 year checkup with a clean bill of health. I have found myself wanting to find ways to give more back to the transplant community in return for the blessings I've been given."*

Tom also brings a tremendous amount of business and executive experience to the Board including thirty years of marketing and sales management, as well as non-profit experience. We welcome Tom Nate to the Board and look forward to working with him.



Tom Nate with son Joshua and wife Irma



Tom Nate, Irma, & Joshua Nate with friend Joel  
Palo Duro Canyon, Texas



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.

# A Touching Donor Family Experience

Mary Hardy

Biateral Lung Transplant  
Cleveland Clinic, May 31, 2002

I know that I have written *AirWays* articles about my donor family before. I am one of the lucky ones who have met and maintain a relationship with my donor family. I have noticed a lot of questions and comments online recently about when and if you should write your thank you letter. Some people have been instructed to wait some amount of time. There has also been discussion about what you should say. Many people feel they don't know how to adequately convey their profound thanks. I can only speak from my humble opinion, and share with you what has been shared with me by my donor family.



Mary Hardy with husband Gary

My donor family has told me the story of the day they received my letter and how excited they all were. It was sent to my donor's elderly father and then shared with his three daughters and three sons. They were very, very happy to hear from me and called me the very next day. There was never any hesitation about meeting in person. They wanted to meet me and I certainly wanted to meet them.

The first meeting was so emotional. I brought my husband and two young daughters. We talked for hours and hours and asked so many questions. I wanted to know about my donor (they called him Junior), and they wanted to know all about my illness and recovery. I think just about every person in the family came to meet me that day, easily over fifty people! It is hard to describe what an honor it was, and still is, to be the person who breathes with Junior's lungs. They were so, so happy to have saved a mother's life. They also knew for certain that Junior would have wanted that too. Well that was 14 years ago and we have had



Mary Hardy with daughter Christine

many visits since then. But even after all these years, someone still usually brings up how happy they are that I contacted them. And so, this is the message that I want to share to those who are uncertain about contacting your donor family. In my humble opinion, there is no need to wait or worry that your words are not adequate. I told my donor family a little about myself and my family and then tried to convey how sorry I was for their loss and profoundly thankful I was to be the recipient of their gift of life. I also told them that I would do my very best to take care of and protect my precious gift. And that is exactly what I have tried to do.

So if you've been uncertain or troubled about writing your letter, I hope you will reconsider. You may not hear back, but that doesn't mean it's not appreciated. Or you may get very lucky like I did, and experience something extraordinary. I will end this story by telling you that my donor family are Amish and have enriched my life more than I could ever explain. The culture difference was no match for the bond that brought us together. We say that I am "part" Amish now, and for that, I am honored and grateful.

*(New Technology continued from Page 7)*

further", said Jamie Bucio, Thoracic Organ Procurement Coordinator at the University of Chicago Medicine.

## Limiting damage to donor lungs before transplant

Lungs can sustain damage during the process to transfer them from the donor and prepare them for the recipient. They can collapse, and, as surgeons begin to ventilate them after transplant, they may not re-expand properly. Fluid can build up within lungs and affect the function of the lung tissue. Brain death of the donor can trigger an inflammatory effect in the lung tissue that can jeopardize the transplanted lung as well.

In addition to these more obvious factors, a number of more mysterious processes happen in the lungs after a donor's death that can decrease the odds of a successful transplant. Lungs may be dysfunctional in the recipient despite adequate appearance in the donor. Two to three out of 10 lungs show signs of such limitations within 72 hours after being transplanted.

"This technology has the potential to reduce that occurrence and allow for better recovery planning of transplant recipients", Wigfield said.

"Losing patients while they are waiting for lungs is unacceptable, but a harsh reality at times due to continued donor limitations", he said. "That's where we would like to see the impact. Reducing that to a minimum would be a huge success."



# 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,  
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

## Transplant Anniversaries

### SEPTEMBER 2015

Name	Transplant Date	Yrs
Elena Khan	9/1/2011	4
Sandra Patrick	9/1/2014	1
David Courtney	9/8/2008	7
Tom Archer	9/11/2006	9
Cynthia White	9/11/2012	3
Maria Trevino	9/14/2014	1
Marilyn Sundt	9/15/2011	4
Cheree Peirce	9/16/2012	3

### OCTOBER 2015

Name	Transplant Date	Yrs
Allen Schwenck	10/6/2009	6
Patrick Dooley	10/18/2000	15
Damian Neuberger	10/19/1997	18
Lynn Shirley	10/19/2009	6
Beth Davenport	10/20/1995	20

### NOVEMBER 2015

Name	Transplant Date	Yrs
Carolyn Blaylock	11/5/2003	12
Cathy Cuenin	11/9/2004	11
Annette Cook	11/19/2014	1
Chuck Schuele	11/20/2008	7
Henk Berends	11/28/2003	12

### DECEMBER 2015

Name	Transplant Date	Yrs
Grace Bachmann	12/3/2005	10
Charles Page	12/5/2008	7
Luann Rizzo	12/10/2010	5
Gage Georgeff	12/14/2009	6
Fred Walker	12/15/2006	9
Betsy Cichon	12/16/2004	11
Dave Griggs	12/27/2010	5

*Congratulations to all who celebrate another milestone!*

(Please see **Events Calendar** continued on page 13)

**NEW MEMBERS AND MEMBERSHIP RENEWALS**  
**SEPTEMBER 2015 — DECEMBER 2015**

**NEW MEMBERS**

Kathryn Bryan	Lydia Burton
Sam Elkurd	Daniel Hackel
Eric Hansen	Cindy Hunt Lukacs
Brad Messer	Ernest Pemberton
David Stockwell	Gail Weadon

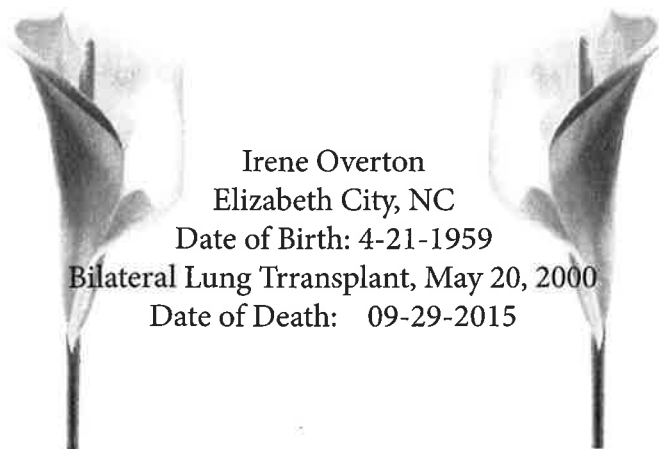
**MEMBERSHIP RENEWALS**

Nikki Addison	Carolyn Aspergren
Grace Bachmann	Martha Becker
Greg Briggs	Martine Cantier
Robert Courtney	Donald Gwynne
Jane Kurz	Scott Larrimer
Maria Loss	Douglas MacIntyre
Julie Martin	Timothy Monahan
Thomas Nate	Garry Nichols
Michele O'Guinn	Cheree Peirce
Brian Puhalsky	Lori Schilling
Alan Schwenck	Anita Tracy
Frederick Walker	Crail White

Dennis Wright

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

**WE REMEMBER**



Irene Overton  
Elizabeth City, NC

Date of Birth: 4-21-1959

Bilateral Lung Trransplant, May 20, 2000

Date of Death: 09-29-2015

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

**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**

Grace Bachmann	Greg Briggs
Scott Larrimer	Garry Nichols
Michele O'Guinn	Anita Tracy
Frederick Walker	Sharon Shackelton

**Donations for Financial Assistance  
Fund**

Garry Nichols	Edith Buckle
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**Donations for Membership Fund\***

Donald Gwynne	Garry Nichols
Cheree Peirce	

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

**Corporate Donations**

Madeline LoPresti Agency, Ltd.  
Allstate Insurance Company  
53 South Washington St  
Hinsdale IL 60521  
(630)789-5882

Respiratory Health Accociation of Chicago

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

//////////////////////  
*(Events Calendar continued from page 12)*

**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 14)*



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

CAROL STREAM IL 601

26 JAN 2016 PM 6 L



Second Wind Lung Transplant Association, Inc.  
1020 Gull Court  
Palatine, IL 60067  
**RETURN SERVICE REQUESTED**

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19810326010



*(Events Calendar continued from page 11)*

## Support Groups & Events Calendar

**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](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 Conf.Rm. 7710

5700 S. Drexel Ave., Chicago, IL 60637

Contact: Fran Hammon, LCSW

[frances.hammon@uchospitals.edu](mailto:frances.hammon@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

[Avryl.Todd@ucsfmedctr.org](mailto:Avryl.Todd@ucsfmedctr.org)