

## Tom Archer Gone Too Soon

The lung transplant community lost a great friend and supporter on March 8, 2020 when, after a lengthy illness, Tom Archer passed away at the age of 64.

Tom served as Board President of both the Second Wind Lung Transplant Association as well as the Second Wind St. Louis Chapter, where he led that Board for 15 years.

Most recently Tom was covering our HELP Line, taking calls from lung transplant patients and caregivers seeking financial assistance, information and advice, and most of all, a friendly voice to help calm their fears. He could do it all.



Tom received a double lung transplant in September 1996 and was passionate about his work with Second Wind as his way of repaying the generosity of his donor family. Like all of our members, he never took this gift of life for granted.

As his family said in their remembrance,

*"Tom will be remembered and cherished for his gentle and generous nature, benevolence, honesty and sense of community. He greatly appreciated life and the world around him and he was a lifelong learner and a patient teacher."*

Due to the ongoing health crisis, services will be held at a future date. You can find the complete obituary at [Dignitymemorial.com](http://Dignitymemorial.com).

## Covid-19: Facts Not Fear

While events are moving much too fast for *AirWays* to try and keep you up to date on all that's happening in relation to the ongoing pandemic, there are many reliable sources of information that you can access for free on your computer or smart phone.

The Federal government maintains multiple websites with Covid-19 information, including the Center for Disease Control ([CDC.gov](http://CDC.gov)) and the U.S. Food & Drug Administration ([FDA.gov](http://FDA.gov)).

The World Health Organization ([who.int](http://who.int)) provides an abundance of information, and Johns Hopkins University ([coronavirus.jhu.edu](http://coronavirus.jhu.edu)) maintains a real time map showing confirmed Covid-19 cases worldwide. In addition, most state governments maintain websites where accurate information can be found.

Major news sites like the New York Times ([nytimes.com](http://nytimes.com)) and the Washington Post ([washingtonpost.com](http://washingtonpost.com)) are providing free access to their Covid-19 coverage. You can download their apps or go to their home pages in order to read the latest news. Likewise, many of our hometown newspapers are providing free digital access to Covid-19 updates on what's happening right around you.

As many of us self-quarantine, social media can be a great way for families and friends to come together in a virtual way, helping to stem the sense of isolation. However, in this time of great uncertainty, where the potential for panic is high, it is vital that we look only to reputable sources for information about the growing pandemic.



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# AirWays

SERVICE THROUGH EDUCATION AND SUPPORT

*AirWays* is published four times per year by Second Wind Lung Transplant Inc. by and for lung transplant candidates, recipients, caregivers, and professionals worldwide.

Every attempt is made to print accurate technical/medical information, but due to time and technical constraints it is not possible to check all submitted information.

Articles printed in this newsletter are for general information only and are not to be taken as professional medical advice. Each individual's situation is unique. Information in the newsletter may or may not apply to you or your circumstances. It is your responsibility to discuss any information herein with your physician to determine whether it is beneficial or deleterious to your health.

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To submit an article for publication in *AirWays*, send an MS Word document to: [phenry2ndwind@gmail.com](mailto:phenry2ndwind@gmail.com).

### General Information

Membership in Second Wind includes a subscription to *AirWays*. To join or for more information, please address please contact Second Wind via email to [phenry2ndwind@gmail.com](mailto:phenry2ndwind@gmail.com) or by phone, toll free at 1-888-855-9463.

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## President's Notes

Jane M. Kurz, President – Second Wind Lung Transplant Association, Inc.



Spring is usually a time to enjoy flowers and sunshine and, for many, the renewed zest for life. These past few months have presented challenges that most people and communities could not have imagined. Transplant recipients and their families have quarantined themselves at home and following CDC guidelines regarding handwashing, wearing masks, preparing for emergencies, and other self-care measures.

As noted in our cover story, it's important to rely on trusted sources such as the CDC, UNOS, NIH and others for accurate information.

Meanwhile your board continues to review Financial Assistance Fund applications, apply for grants to fund our many initiatives, update the web site, and maintain our Email Support Group and HELP Line.

We recently gained two new board members: Ruth Magnus, who received her lung transplant 11 years ago and Melissa Burke, a Lung Transplant coordinator at the University of Pennsylvania.

In January the board elected officers for one-year terms. I remain as president, Frank Shields continues as Vice-President, Patrick Henry is now 2nd Vice-President, and Ruth Magnus accepted the Secretary position.

We were all saddened by the passing of our former president and board member, Tom Archer, who supported this organization for almost 15 years. Most recently he was monitoring the HELP line. We, along with the rest of the lung transplant community, will miss him.

Cathy Cuenin, a lung transplant recipient and book author, has volunteered to take Tom's place by covering the HELP line.

In the last newsletter I presented the annual goals and the board has been working diligently on them. There are several creative efforts ongoing to increase memberships, and total numbers remain unchanged despite losses through deaths and non-renewals. If there is anything you think the organization can do better, please contact us. And remember, we are always looking for additional board members who will share their wisdom & experiences.

During this pandemic there has been some chaos surrounding the lack of appropriate equipment, sanitizer, and other resources. Healthcare providers, trying to protect their patients and staffs, are engaging more in telemedicine as they assess those at home. Still, many of us have had to confront the real possibility of our death or the death of a loved one due to the COVID-19 virus.

Communities that have had better outcomes were those that had disaster plans in place and were ready to implement community interventions. Planning was the key. We should take note of that and prepare for the next crisis.

Chaos is a part of our lives but how we respond to it is something we can control, and one area is the use of advance care directives.

All transplant candidates complete a set of advance care directives with help from their transplant team. It is placed in their records and, hopefully, they shared it with their significant other and support person. This is something that all people should do, regardless of their health status. Unfortunately, studies show that fewer than 20% of people living in the community have created their own advance care directives. This is different for those in nursing homes where 70% of residents have one. Culture may also play a role in who are creating advance directives. Researchers report low rates among Asians-Americans and African-Americans and suggest that part of the problem is a lack of opportunity to discuss advance care directives.

You who have completed advance care directives need to be the leader in your family and start the discussion. Thinking about preferences as to how you or your family members would want to be treated during a health crisis is important. These are often difficult conversations to have, but using a few guides might help get them started. The purpose of these talks (& there should be several) is to help everyone know the person's wishes and values. It will assist those who are making decisions when the person is unable to speak for themselves or use good decision-making skills without emotion clouding their judgement.

Conversations about advanced directives need to occur *before* a health crisis occurs. An excellent guide that others have used successfully is "Five Wishes", a free, comprehensive document available on the internet ([www.fivewishes.org](http://www.fivewishes.org)) that takes you through the five most important things to talk about when considering advance care planning. Each section has questions or concepts for you to consider and a space for you to add what you want. They are as follows.

Wish One: who is the person I want to make health care decisions for me when I cannot make them for myself?

Wish Two: the kind of medical treatment I want or don't want.

Wish Three: how comfortable I want to be. This is not a simple pain management issue; it asks more complex questions, e.g., whether or not being alert is more important than being drowsy but having less pain relief.

Wish Four: how I want people to treat me.

Wish Five: what I want my loved ones and health team to know about my condition and me.

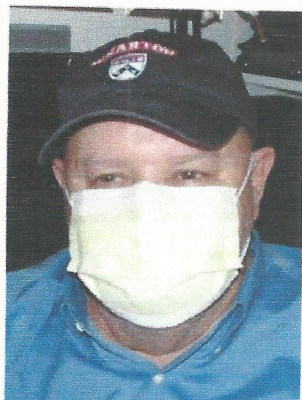
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## Stayin' Alive

By Tim Adams, Member-Second Wind Board of Directors  
Lung Transplant Recipient-19 June 2017

*(NOTE: This was to be the first part of an ongoing series on how to protect our new lungs for the long term. The sudden Covid-19 pandemic requires that important new tips take priority at this time, so for now we're sharing just this introductory series will resume when things return to "normal".*



When I left Temple Hospital, one of the nurses who had been a constant uplifting presence during my stay, patted me on the back and gave me a simple, lifesaving bit of advice. "Don't forget to use your mask—all the time." As a Lung Transplant Patient (LTP), that simple idea has become a talisman, reminding me constantly of all the things I must do to preserve the second chance at life I've been given.

Like many LTPs, IPF almost killed me. Luckily, family, friends, and a host of medical professionals came together in June of 2017 and saved my life. I owe it to myself and to all of them to ensure that the precious gift they gave me is sustained. Fortunately, the odds of me staying alive are pretty good as long as I don't break the rules.

Why do we need rules?

Because we are creatures of habit, and that leads to Complacency.

Complacency can sneak up on you as soon as the end of your first year! You're feeling good, you're feeling like your old self and you get a little "lazy." I know, based on my own experience and on comments from other LTPs, that it can happen to any of us.

First, I first noticed that I was getting out of my car without a mask. I don't know why, but it started to happen even though I had a fresh mask hanging from the turn signal stalk in my car, and one over the sun visor. Sometimes I forgot to put it on.

Then, after talking with and mentoring other LTPs patients I concluded that something else happens that makes some of us

think we are "going to live forever!" What is simple, we all want to return to "normal"!

I'm sure most of you have heard someone say continue to need that awful mask—it makes me Or. "I'm pretty sure I don't need to see that doc months. I feel fine!" How about, "I'm going to c half because they just cost too much." One of my mind game I play when, forgetting my mask in a myself. "I'll just avoid people as best I can instead out to the car to get the mask!"

Some might ask, "Where in the world did complacency come from?"

I believe it's because we are thinking that moving lives in the "old" normal fashion is OK. It's just n accept our new normal.

Complacency doesn't just arrive one day, it sneak feel better and we become more comfortable. W shape, people tell us how good we look or we loo and see how well we look and we get complacent, post-transplant that we celebrate we get even mo It seems as normal as rain.

The key to avoiding complacency is that of maintai Vigilance = Stayin' Alive.

The Flu, and now the Corona Virus demonstrat vigilance. What else is lurking out there? Wh vigilance can help us avoid the danger. The published a checklist and a few simple rules Covid-19, but there are many more concerns for a patient. In future articles I'll share some of my n *Alive* (with apologies to the Bee Gees).

### *President's Notes continued*

The advantages of this tool are that it is written in everyday language with no confusing medical terms. It covers personal, spiritual, medical, and legal wishes in one document. It contains all the information needed to guide you through these discussions, conversations that serve to reduce your family's anxiety at a

Your challenge now is to start the conversation wi share your thoughts and wishes, and learn what tl The goal is to listen carefully without judgemen right or wrong answers. The real question is: W decision for you and your family?



## Quaran-Tales:

The Second Wind Email Support Group has been abuzz lately with members sharing tips, thoughts and words of encouragement in this time of pandemic. Here are just a few excerpts. (If you'd like to join the discussion, see the article on page 10 to find out how.)

*"I am used to having my grands over two to three days a week. Now I meet them in the park with their parent and watch them play from afar. One...suddenly stopped and screamed: 'I want to go to Grandma's. I want my raspberries and cream!' Obviously I am not the only one suffering from the changes.*

*I compare this to what my life was like before my transplant when I was housebound, on oxygen and down to 14% lung function. Piece of cake, really. "*

*- Peggy Seanor*

*"I get my prescriptions at the pharmacy and use their drive up window. I have my Clorox wipes in my coffee holder...when the transaction is complete... wipe the credit card, then the steering wheel because that is where the clip board touched when I signed the receipt and finally my hands. "*

*- Betsy Cichon*

*"Missing my boys, one across the country, one living in town...I took a walk with (him) staying 6 ft apart. Washing hands a lot, especially after touching anything that was not already in the house (e.g., mail). Basically, trying to stay safe without feeling neurotic about it. Thinking about you all. We're ALL in this together! "*

*- Denise Jacobs*

*"I've been working at home...this week I was asked to go to a govt building...my lung tx doc....said it was safe for me to go, provided I did the following:*

- 1. Wore 2 masks ... an N95 mask with dust mask over top.*
- 2. Don't touch surfaces, esp hard surfaces since the virus can live longer there, and*
- 3. Go when others aren't there.*

*I have 25 yrs practice...but find many healthy people to be fairly stupid about avoiding germs. Passed a guy in hallway yesterday who began laughing when he saw my face mask. "*

*- Mary Peters*

*"I am...22 years out and have been social distancing for that long too. It's instinctive.*

*My wife still goes to the grocery...and we have 4 kids... even though they are doing nothing outside the home could still catch something. I am sleeping and working on our 3rd floor. When I do see my family, I stay about 6 feet from them. It's drastic but these are drastic times. "*

*- Lee Cohen*

*"All groceries are being delivered. My wife wipes them down...(and) takes her clothes off afterward and then showers. She did this on her own....Just noticed my mail carrier is wearing gloves and mask today. "*

*- Jeff Birgbauer*

*"Our children are doing the shopping for us and delivering to our door. We wipe everything down and wait for it to dry before putting away...have had some video time with kids and our teenage grandchildren which has been really special.*

*Wishing everyone good health and pray we can all stick this out till the world has healed. "*

*- Ruth Magnus*

*"I'm keeping occupied by walking my dog, discovered lots of exercises programs on YouTube...(plus) books, movies, puzzles. My church has several on line services a day. All and all life is pretty good here, we are all so blessed to have these lungs. "*

*- Shiranne Simmons*

*"I live at the beach in Kitty Hawk, NC. Our island is closed to visitors and part time home owners! Nice for people that live here year round. We don't have to fight for supplies. We've been walking our pup, spring weather permitting, biking, walking and catching up on Netflix shows! My husband is the "go out and get stuff" guy.*

*Y'all take care! "*

*- Beth Davenport*



## Welcome Melissa Burke Our Newest Board Member



I am very happy to be a part of the Second Wind Board in the role of medical consultant!

In this article, I would like to give our members a glimpse of how I became a lung transplant nurse practitioner (NP) and why I love my job. When I tell my patients how I became a lung transplant NP, I usually say that, initially, it was

by chance, but now I cannot imagine working with any other patient population.

I started my nursing career on a busy cardiac surgery floor in Washington D.C. in 2006. My career then brought me back to Pennsylvania as a telemetry and trauma registered nurse in 2009. In 2012, I decided to challenge myself further by becoming an ER nurse and simultaneously enrolled in the Masters program for Nurse Practitioners at the University of Pennsylvania. I remained in the ER for 3 years in a community setting and then transitioned to an urban center at the Hospital of the University of Pennsylvania.

Being an ER nurse taught me so much—both personally and professionally. I learned critical care skills, appropriate utilization of the ER, how to carefully triage patients, and most importantly, how to best provide comfort and care for patients when they are most in need.

From the ER, I started my first NP job on an inpatient medical transplant team. I chose this because I was interested both in transplant and general medicine. I was in awe of the resilience of and the medical complexity faced by the lung transplant patient population. I decided to transition from the inpatient side of care to an outpatient NP coordinator because I felt I was missing the longitudinal care and connection providers have with their patients in the outpatient setting.

Having been asked to discuss the challenges that I face on a daily basis, I will start by saying that in this role, I truly learn something new each day due to the complexity and emerging science involved in lung transplantation. One of my biggest challenges is finding the balance between ensuring my patients have the best quality of life, while keeping them safe and healthy. This could not be more present in my mind as we all endure this current crisis, the COVID-19 pandemic. Sometimes finding this balance is difficult because it may require a hospitalization instead of celebrating a wedding, traveling, or simply getting labs twice a week versus monthly because of a new medical

“normal life.” Any care decision I make in light is harder and requires extra coordination, planning strategies to ensure my patients are safe and me getting the best care. The responsibility I feel weighs heavily on me because I believe lung transplants have been through so much already and I always want quality of life to be worthwhile. So, making decisions that impacts quality of life is something I always find I do. I think what I have learned is that these decisions are made as a partnership between the patient and the team, as well as utilizing the appropriate prevention to combat illness.

COVID-19 is changing our way of delivering care and not change the way we care for each other in our community. I am honored to serve on this board and utilize the Airways magazine as a platform to cover topics that can help guide patients and their care to successful outcomes.

Be safe, stay well, and continue to stay positive during this difficult time.

- Melissa Burke MSN, CRNP

### Editor's Notes:

- While we'd intended for this issue to focus on a milestone—Second Wind's 25th Anniversary—things, the Covid-19 pandemic upended our plans. So, we did include a look back at all the volunteers on SW's Board over the years, as well as articles about the pandemic, including where to go to keep safe along with personal stories from our members dealing with it.
- This issue also describes the many different ways we've connected with Second Wind and other members through our website and Email Support Group (see page 11). Now more than ever, we're in touch.
- Transplant recipients and those awaiting one know how important it is to be mindful about infection. An article from Board member Tim A. (4) describes how, because of the ongoing pandemic, it's more critical than ever.
- We print Transplant Anniversaries in each issue. Due to the number of years since the recipient's transplant, a calculation error I made in the last issue, I am providing an accurate count for those who were celebrating their Transplant Anniversaries. As a result I owe you credit for



# Lung Transplant Foundation

## Joseph J. Carter Mentorship Program

*(NOTE: Aware that we at Second Wind are not the only organization that offers peer mentor support to transplant patients and their families, we offer this article about another source for this valuable service.)*

"I have been blessed with a renewed opportunity to live."

Jerry Gilliland's story is one of deep gratitude. He received a double lung transplant June 2, 2015, and spends every day thankful for more quality time with Tina, his wife of 38 years and with his children and grandchildren.

"I am thankful for my gift of life and forever grateful to my donor," said Jerry.

Like many others who have received a live-saving organ transplant, Jerry decided to return the kindness he experienced during his transplant journey by becoming a mentor for other lung transplant patients through the Lung Transplant Foundation (LTF) Joseph J. Carter Mentorship Program.

Launched in 2017, the LTF Mentorship Program has engaged more than 200 lung transplant patients and caregivers.

When someone has been newly diagnosed with an end-stage lung disease, they may feel alone and uncertain about where to turn for help, especially when they learn that a lung transplant is required.

"The lung transplant process is such a long and difficult one, it is important for recipients to receive support from those who have gone before them," said Grey Hall, who was mentored by Gilliland through the LTF program. "The mentorship program provides support and an important 'experiences check' for those who have been given a second chance at life."

The LTF Mentorship Program connects transplant recipients and caregivers with trained volunteer Mentors who have gone through the lung transplant process themselves. Through this free program, Mentors provide support and information for pre-and post-transplant recipients and their families.

Janice Sutton joined LTF as the Mentorship Program Manager in 2018. Since receiving a double-lung transplant in 2012, she has devoted her time to her family, as well advocating for organ donation and finding ways to educate, inform, and give back to the transplant community.

Our Mentorship Program is made up of a team of volunteers who experienced the lung transplant process, either as a patient or caregiver," Janice said. "They provide support, encouragement and compassion to the transplant community and to each other."

Mentors have a compassionate, comprehensive and first-hand understanding of the struggles and challenges recipients will face or may have already experienced. The comfort and support provided by Mentors are vital for pre- and post-lung transplant patients and caregivers.

Knowledgeable recipients and caregivers are less stressed and better able to handle the demands throughout the transplant process. Well-supported lung transplant recipients and caregivers improve overall compliance and success.

The program provides an essential link between people living successfully following their transplant experience and those new or adjusting to life after transplant.

"I was a Mentee before signing up to be a Mentor," said Maqsuda Kabir. "I had a very positive experience. Just knowing my Mentor also is a lung transplant patient was even more comforting. This was such a blessing in the early stage of my post lung transplant recovery. I feel blessed to be involved with such a wonderful organization like LTF. Thus, I've decided to take on a Mentor role and give back."

The Mentorship Program is a one-on-one confidential relationship for the sole purpose of providing support and guidance. Mentors are not medical professionals and do not provide medical advice. All Mentors must complete live training that includes, listening skills, organ donation and transplant "Frequently Asked Questions", tips and tools, as well as role play scenarios.

The Mentorship Program is named in honor of Joseph J. Carter who looked for a way to connect with other people going through a similar experience while he was waiting to be listed for a lung transplant due to a rare congenital lung disease.

Carter died in 2008 at age 38. His wife, Shari, and their sons Zachary and Aiden (who was born 2 months after Joe's death), joined forces with LTF to support the Mentorship Program.

"Joe would go out of his way to help anyone," said Shari. "He searched for a program like this in his time of need. He would be honored to be a part of something that will help so many others. This program is a beautiful tribute to a life lost way too soon."

For more information or to request a mentor, visit the LTF website at [lungtransplantfoundation.org](http://lungtransplantfoundation.org).



## Leap for Life

(Lung Transplant for Lymphangioleiomyomatosis)

As we begin this adventure, my arms reach wide with ease,  
my grin is great, and my feet spring lightly into the air,  
kicking up behind me, creating a splash of glee,  
all while breathing is deep—yet in time  
the smile begins to lose its luster,  
breathing becomes labored,  
arms and feet fatigue  
energy is drained,  
as life begins  
to fade  
away.  
As we  
move out  
the other side  
of this tale a wide  
new grin begins to form  
at the corners of my lips and  
I gasp, filling my chest with breath,  
my arms once again extending as I jump  
with joy, amazed, yet afraid at first, wondering  
if I can trust this; in time I learn to trust and accept  
what comes and I am nourished by a deep well of gratitude  
for the family who gifted the lungs and for my leaping companion.



## The Hose Pre-transplant

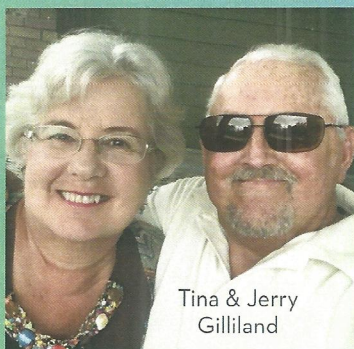
It seems as though I have a nose that runs on just... forever.  
It's just a hose, that's up my nose, to keep me in the pink.  
It's long and slender, even tender, but one I'd like to keep,  
As long as I have need of it, to keep my lungs in sync.  
One would think I didn't know, a nose that long is odd,  
It's just the hose that's up my nose, to keep me from the brink.  
It follows me where 'ere I go, it goes just for the ride,  
It even goes to bed with me, to make sure that I arise.  
I have a cart that follows too, it seems it is on a tether,  
It's just so I don't wonder off, no matter what the weather.  
And in this cart, there rides a tank, that carries all my air,  
So I can breath in just like you, without a thought or care.  
They've been my friends for years it seems, they stay close to my heart,  
But when I got new lungs you see, it's then we can part.  
I'll miss the hose that's up my nose, but parting's not sweet sorrow.  
For new lungs to this "old grey frame" can add some "new Tomorrows".

- Monty (2003)

### If you are going through a lung transplant, we can support you

"I have been blessed with a renewed opportunity to live. I look forward to sharing my experiences."

— Jerry Gilliland



Tina & Jerry  
Gilliland

To request a mentor, please visit:  
[lungtransplantfoundation.org/mentorship/](http://lungtransplantfoundation.org/mentorship/)  
For inquiries, email:  
[ltfmentor@lungtransplantfoundation.org](mailto:ltfmentor@lungtransplantfoundation.org)  
Free. Confidential. Anywhere in the U.S.



Lung Transplant Foundation Joseph J. Carter  
**Mentorship Program**

## Lady in waiting

Breathing  
Once taken for granted  
"Hal", tethering me like an astronaut, my life support  
Level going higher, higher...  
Breathing in, and breathing out  
Watching my body from above  
Waiting and wondering what will happen next  
One "Hal" turns into twins in tandem  
Realized fears I never thought of  
Will I make it to the car, or house, before I run out?  
When I get home, is the bathroom or oxygen more urgent?  
Will the power go out? "Hal", don't fail me now!


Friends called me "Lady in Waiting"  
Did I wait too long to start this process?  
So many tests  
Then, the call!  
Relief in sight!  
Fifteen days in that room,  
Staring at those walls  
Seeming like forever  
Ups and downs,  
Highs and lows  
Is it working?  
Yes! I'm one of the lucky ones!  
So grateful...  
To the Divine,  
To my donor,  
To doctors, nurses, therapists, family, friends  
Still breathing  
Cheating death  
More time  
Breathing

- Denise Jacobs


*Bilateral lung Transplant, 2017*


*Ohio State University Medical Center*





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## Time To Explore: 2ndwind.org

Second Wind maintains a website that has an useful information about the organization, its issues affecting lung transplant recipients and the

Here's but a partial list of the things you'll find there:

- PDF copies of past AirWays newsletters;
- Personal stories written by transplant recipient;
- Nutritional Advice for pulmonary patients;
- Detailed information on Lung Transplant Center by State and Country;
- "Financing a Transplant" & Second Wind Assistance Program";
- Bios on many of the SW Board of Directors;
- List of books about lung disease and transplant;
- Caregiver Links: resources for people providing care for lung transplant recipients and anyone with pulmonary disease.

The website is constantly being updated, so if you haven't visited in awhile, now's the time to get in there and

## Second Wind Email Support Group

Second Wind maintains an Email Support Group whose members consist of people waiting for a lung transplant, who have had a lung transplant, or who act as caregivers for a lung transplant candidate or recipient. It's a virtual online community where people ask questions, share comments, personal stories and links to Internet articles on the latest research.

Using an email format, members post items for all to read and respond to, either directly to the sender, or to the whole group, though you are not obligated to do either. Members have the option of simply reading posts from other members.

Recent threads have included topics such as:

- What steps are you taking to protect yourself from Covid-19? (Turn to page 5 for a sampling)

- What are the best hand sanitizers to get?
- Do you use a sinus rinse on a regular basis, if so, what kind?
- Congratulatory messages to a member celebrating their 19th year post-transplant.
- Home spirometry—who is doing it on a regular basis?

**PLEASE NOTE:** all members understand that, in discussions sometimes include information on medical options, they never offer specific medical advice and members should never act on information they receive without first checking with their transplant center.

If you are interested in becoming part of the community, please contact Tom Nate via email ([tnate@gmail.com](mailto:tnate@gmail.com)) and he will add you to the group. If at any time you don't wish to continue to participate,



## Transplant Anniversaries

### FEBRUARY 2020

Name	Transplant Date	Years
Paul Albert	2-10-93	27
Sandra Anderson	2-3-01	19
Cheryl Keeler	2-3-05	15
Peg Matthews	2-16-10	10
Jim McClure	2-24-18	2
Raju Shah	2-22-19	1

### MARCH 2020

Name	Transplant Date	Years
Robert Glim	3-7-10	10
Robert K. King	3-20-08	12
Edward Kuhn	3-4-08	12
Lois Peddgree	3-2-19	1

### APRIL 2020

Name	Transplant Date	Years
Aunjelique Anderson	4-6-19	1
Gary Bland	4-7-09	11
Greg Briggs	4-30-97	23
Kathryn Bryan	4-9-16	4
Edgardo Diaz	4-10-19	1
Teresa Figueredo	4-29-16	4
Bobbie Hicks	4-23-19	1
Jose Navarrete	4-25-19	1
Ernest Pemberton	4-14-16	4
Shiranne Simmons	4-8-17	3



## Second Wind On Facebook

If you're a fan of Second Wind and a Facebook user, consider joining our private Facebook Group: Fans of Second Wind Lung Transplant Association. Like the SW Email Support Group (see previous page), it's another virtual community where members share information, advice, comments and links to websites of interest to the lung transplant community. There are currently 569 active members in the group.

You can find us by signing into your Facebook account and searching for Fans of Second Wind, or by going to our website, 2ndwind.org and clicking on the FB link at the bottom of the home page.

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## A WALK THROUGH TIME:

### Second Wind Board Members: 1995 – Present

The Second Wind Lung Transplant Association could not have survived the past twenty-five years without the contributions from so many volunteer board members. We wish to recognize and say thanks to each and every

Note that while many members served multiple terms they are listed here only once, based on the first year joined the board.

#### 1995 – 1999

Steve Love\*\*, Judy Wright\*\*, Tom Wright\*\*, Don Isaman\*, Kathy Isaman, Dale Burnmeister\*, Paula Burnmeister, Nancy Camp\*, John Camp, Kelly Helms, Sandi Olson, Sherry Russo, John Russo, Connie Wagner, Paul Anderson\*\*, Josie Langdon\*, Matt Robertson, Dick Wyatt\*, Karen Rodgers, Diane Padget, Richard Heering, Evelyn Heering\*, Paul Brooks, Bill Churchill, Bob Hudson, Walt Craig, Ron Peterson.

#### 2000 – 2009

Kathryn Flynn\*\*, Joanne Schum\*, Larry Kaufman, Melissa Reta\*, Carmen Walser, Mary Parker, Russell Adair, William Kanasky, Erin Odell\*, Steve Bunsen\*\*, Tammy Campbell, Pauline DeLuca, Lori McReynolds, Nancy Yoakum\*, Janet Walin\*, Tom Archer\*\*, Ruth Donahue, Susan Koujak\*, Garry Nichols\*, Michele O'Guinn, Daminan Neuberger\*, Milton Goldstein, Judy Ryan\*, Mary Hardy\*, Cheryl Keeler\*\*, Jane Kurz\*\*, Sharon Barlow, Tiffany Christensen, Julie Martin, Melody Pierson.

#### 2010 – 2020

Dharta Desai Ahora, Tina Orlita\*, Larry Pontius, Steve Schumann\*, Robert Lohstroh, Diane Young, Ken Carrell\*, Jack Austin, Tom Barbour, Gary Bland\*, Frank Shields\*, Ross Pope, Tom Nate, Eric Harned, Judy Neuberger, Tim Adams, Patrick Henry\*, Maria Molina, Melissa Burke, Ruth Magnus\*.

*\* Designates those who served as an Officer*

*\*\* Designates those who served as Board President.*



# DONATIONS

## GENERAL FUND

*Katie Moyer*

*Lorenzo Pope*

*Ron Zimmer*

## FINANCIAL ASSISTANCE FUND

*Holly Hahn-Baker*

*Patrick Henry*  
*(IHO Frank Shields)*

*Tim Monahan*

*Bob Trezek Insurance Services Co.*  
*(IHO Frank Shields)*

*St. Wendelin's Knights of Columbus*  
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*Mathew Zagorski*  
*(IHO Frank Shields)*

## Donations

### *In Memory of Eric Lehto*

*Bonnie Barron*

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*John Paras*

*Mitchel & Cheryl Parent*

*Kylie Rogers*

*Alfred & Ethel Tetreault*

*James & Betty Tsiolis*

*Virginia Van Epps*

*Paul and Sharon Wakel*

We would also like to thank those confidential members who made a donation. During the months of January through March, 2020 we received two donations from members who previously asked to be listed as "confidential".

We thank all of you for your generous donations to Second Wind Lung Transplant Association, Inc.

## Efforts Ongoing To Defeat Chronic Rejection

The 2019 Nobel Prize in Physiology or Medicine was awarded to three scientists who discovered how cells detect and respond to changes in oxygen levels, research that has implications for treatments to mitigate chronic rejection in lung transplant patients.

Due to chronic rejection, the medical term for which is "bronchiolitis obliterans syndrome", or BOS, lung transplants do not last as long as other transplanted organs, but a piece of their research may help to change that.

A portion of the award was granted to Gregg Semenza of the Johns Hopkins University School of Medicine for the discovery of HIF-1 alpha, a protein that switches genes on and off in response to low oxygen levels. This protein and a companion molecule, HIF-2 alpha, play important roles in the health of blood vessels, the loss of which can contribute to failure of lung transplants.

Mark Nicolls, a pulmonologist from Stanford began publishing research with Semenza based on increasing the HIF-1 and HIF-2 alpha levels in animal models of lung transplant. The increased supply of these proteins resulted in transplanted organs that were healthier and lasted longer.

The researchers patented a medication to turn up HIF-1 alpha levels, a fluid that surgeons would apply to transplanted lungs at the time of the operation to enhance natural blood vessel repair. The treatment is still in the process of being brought to market. Meanwhile, Nicolls and Semenza are seeking a way to apply the same principles to chronic lung transplant rejection.

"Lung transplant rejection is like a heart attack of the airways: You lose blood supply and get a scar, which turns into chronic rejection," Nicolls said. The hope is that by turning up level of HIF proteins it would slow or reverse the process.

\* \* \*

There are other research efforts underway to address chronic rejection in lung transplant patients. As outlined in the November issue of AirWays, Breath Therapeutics, a company founded by a group of people with expertise in aerosol therapy, drug development and rare diseases, is developing a drug to treat BOS. It is a formulation of cyclosporine that is inhaled through a nebulizer and delivered directly to the lungs

The drug is being tested in two adult lung transplant recipient studies, known as BOSTON-1 and BOSTON-2, and Breath Therapeutics has initiated two additional clinical studies for the treatment of BOS known as BOSTON-3 and BOSTON-4.

Questions regarding the BOSTON studies can be sent via email to [patients@breath-therapeutics.com](mailto:patients@breath-therapeutics.com).

It is encouraging to realize that the battle against chronic rejection is being waged on multiple fronts. Look for more information on these efforts in future issues of AirWays.



## Support Groups & Events Calendar

### Lung Transplant Support Groups

*(PLEASE NOTE: in light of the ongoing pandemic, be sure to check to see if a group is still meeting, whether in person or via tele/internet connection.)*

#### 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, 2 pm at Chris' Pancake and Dining, 5980 Southwest Ave, St. Louis, MO 63139

Contact person: Ken Schanz, President, (618) 974-3971, kenschanz@secondwind.org.

#### Loyola University Medical Center

Pre-transplant, post-transplant patients, & support person(s).

First Tuesday every month, 11 AM - 12:15 PM

Third Tuesday every month, 6:30 PM

All meetings: EMS building, 3rd floor, Rm 3284

2160 S. First Ave, Maywood, IL 60153

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

Shands Cancer Hospital, South Tower, 5th Flo  
1515 SW Archer Rd., Gainesville, FL 32610

Contact: Micki Luck, nodurm@shands.ufl.edu  
Phone: (352) 519-7545

#### University of Washington Medical Center S Pre- and post-transplant Support Group

Support group meets the second Tuesday of the month at 12:30 – 2:30 PM in a conference room off of the 2nd floor. Many people meet in the cafeteria to have lunch meeting.

Contact person is Angela Wagner, MSW at (206) 616-2000 email wagnera@uw.edu

#### 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) 353-138

#### 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 – 1:00 pm

Mercy Conference Room Contact: Kathy Lam  
Kathy.Lam@DignityHealth.org Phone: (602) 442-2222

#### University of Chicago Medical Center

Lung Transplant Support Group for transplant and those who are listed. Third Wednesday of the month 5-6:30 pm. Center for Care and Discovery (CCD) 7th Floor Conf.Rm. 7710



## Support Groups & Events Calendar

*continued...*

### 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)

### 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. Luke's 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.

### UCLA Lung Transplant Support Group

Ronald Regan UCLA Medical Center

757 Westwood Plaza Drive, Los Angeles, CA 90095  
8-120 Conference Room

12:00 to 1:30 pm

Stephanie Aguirre, MSW, ACSW Phone: (310) 267-9728  
saguirre@mednet.ucla.edu

## New Members

In addition to the names listed below, during the months  
of January through March, 2020 we had five other new  
members who asked to be listed as a "confidential"  
member. Thus, we do not share their information unless  
we have written permission to do so.

We do thank all of you for joining Second Wind Lung  
Transplant Association, Inc.

Aunjelique Anderson

James Austin

John Berti

John Della Jacono

Karina Hallinan

Michael Harmon

James Helms

Sheryl Helt

Bobbie Hicks

Karen Joy

Sonia Joseph

Michael Long

Jose Navarrete

Helen Nichols

Joanel Read

Helen Sanders

Carol Schutt

Raju Shah

David Somerville

Danette Ward

Jennifer Wilcox

## Membership Renewals

In addition to the names listed below, during the months of  
January through March, 2020 we had renewals from two  
members who have asked to be listed as a "confidential".  
Thus we are not allowed to list those renewals.

We thank all for your membership renewals with Second  
Wind Lung Transplant Association, Inc. We greatly  
appreciate that.

Stephanie Bauersachs

Brian Conley

John Douglas

Gage Georgeff

Gwen Herron

Robert King

Peg Matthews

Tim Monahan

Katie Moyer

Michele O'Guinn

Lorenzo Pope

Jeanne Roberts

Michael E. Thomas

Brenda Withers

Ronald Zimmer





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AirWays with friends,  
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