

Cystic Fibrosis: Breakthrough Treatment Approved by FDA

The U.S. Food and Drug Administration (FDA) has approved Trikafta, a new drug therapy to treat patients 12 years and older who have a gene mutation estimated to affect 90% of the cystic fibrosis population, or roughly 27,000 people in the United States. (The safety and effectiveness of Trikafta in patients younger than 12 years of age have not been established.)

Cystic fibrosis is a progressive, life-threatening disease, which results in the formation of thick mucus that builds up in the lungs, digestive tract, and other parts of the body. It leads to severe respiratory and digestive problems as well as other complications such as infections and diabetes. Cystic fibrosis is caused by a defective protein that results from mutations in the CFTR gene.

“Today’s landmark approval...(makes)...a treatment available to most cystic fibrosis patients, including adolescents, who previously had no options, and giving others in the cystic fibrosis community access to an additional effective therapy,” said acting FDA Commissioner Ned Sharpless, M.D.

Trikafta is a combination of three drugs that target the defective CFTR protein. It helps the protein made by the CFTR gene mutation function more effectively. Currently available therapies that target the defective protein are treatment options for some patients with cystic fibrosis, but many patients have mutations that are ineligible for treatment. The efficacy of Trikafta was demonstrated in two randomized, double-blind trials. In each trial, the primary analysis looked at increases in the percent predicted forced expiratory volume in one second, known as FEV1, which is an established marker of cystic fibrosis lung disease progression. Trikafta increased the FEV1 in both trials.

The FDA granted approval for Trikafta through their “Fast Track” and “Orphan Disease” processes, which provide incentives to encourage

the development of drugs for rare diseases. Drugs approved under expedited programs are held to the same approval standards as other FDA approvals. Because of Trikafta’s benefit to the cystic fibrosis community, the FDA reviewed and approved Trikafta in approximately three months, ahead of the March 19, 2020 review goal date. The approval of Trikafta was granted to Vertex Pharmaceuticals Incorporated.

Patients with cystic fibrosis should speak with their health care professional and have tests performed to determine which gene mutations they have. The presence of at least one F508del mutation should be confirmed prior to treatment.



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AirWays

SERVICE THROUGH EDUCATION AND SUPPORT

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

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

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We welcome contributions; however, we reserve the right to edit submissions for length and content. Any changes made will be reviewed with the author whenever possible. Original articles printed in *AirWays* become the property of the Second Wind Lung Transplant Association, Inc. and may not be reprinted without permission from the Editor.

To submit an article for publication in *AirWays*, send an MS Word document as an attachment to: phenry2ndwind@gmail.com.

General Information

Membership in Second Wind includes a subscription to *AirWays*. To join or change your address please contact Second Wind via email to 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.



We have started a new decade and many of us created new goals for the coming year. It is also customary for organizations to reflect on their mission, goals and strategies to achieve those goals. Our board meets every other month by conference call to discuss these. We remain dedicated to improving the quality of life for lung transplant recipients, candidates, and people with related pulmonary concerns

and their families by providing support, advocacy, education, information, and guidance. Through a spirit of service we strive to add years to their lives and life to their years.

Organizations are like relationships. If you do not nurture them, they disintegrate and disappear. An organization like Second Wind needs many dedicated people to focus on our goals as outlined below. Each member should select a goal and consider how they can contribute to it! Let me review the 2020 goals that the board recently approved.

First, we want to increase the number of dues paying members by 10%. In 2019 UNOS (United Network for Organ Sharing) reported more than 2400 new adult lung transplants and 1500 candidates yet our membership remains relatively unchanged. Why are our newest transplantees not part of this group? Every member receives a recruitment flyer with their renewal notice that you can share with others. You have the opportunity to share your transplantation knowledge at your center waiting rooms, the dental office, the gym, your church, your support groups, etc. Social workers at all the centers also receive our newsletter and flyers to display, yet many still do not know about Second Wind and its resources. What are you doing to help spread the news?

If the cost of membership is truly an issue, several members donate to a membership fund so that dues can be waived for the first year. (However, the organization cannot afford to waive everyone's membership fees.) Also this past year the board reduced membership fees for health professionals to encourage their joining.

I had been mailing the renewal notices for 10 years and this year Gary Bland started contacting those who neglected to renew. (Mary Hardy, a long-time member, is now maintaining the member database from which renewal information is gleaned.) When contacted, many report that they simply mislaid the notice. And, sadly, this is often the way we discover when a

member has passed. Gary continues his support by talking with the grieving family member.

A second goal is to keep SW as an active on-line presence, so all have access to the latest information. Tom Archer, member and former President, maintains the Help line, listed on the web page, and answers questions daily. Two directors review the web site and update it as needed. More hands to help here would be appreciated. The Facebook page, *Fans of Second Wind*, is usually quiet but Damian Neuberger and others provide frequent informational postings. Frank Shields has contacted other organizations to list us on their web sites and we have listed them on our web site. Tom Nate nurtures the list serve while he also works full-time and addresses his own health issues.

A third goal is to continue sharing accurate information with all members and centers via the newsletter, *AirWays*, issued four times a year. The cost of publishing and mailing the newsletter accounts for a major portion of our budget. Patrick Henry has assumed the editor's position and he welcomes professional articles, personal stories, and other contributions. Often it is a question from a member that stimulates the search for an expert for an article.

A fourth goal is to increase the number of donations to the Financial Assistance Fund. It is clear that many need a little financial support for unexpected costs associated with transplantation and this fund helps to meet that need. (See the article on page 9 for more details.) We were fortunate in 2019 to receive a large number of donations in honor of one of our members, the late Linda Stocke, but the need continues to grow. Board member Eric Harned sends notes of appreciation to all donors. Board member Frank Shield recently applied for a foundation grant but it was declined. He plans to resubmit. This is an area where someone with grant experience could serve as a volunteer collaborator.

A final goal is to increase the number of new board members. Every December Garry Nichols sends a notice of board openings and elections. Several of our current directors have served for many years and now need to focus on their own or their family's health. Soon they may leave the board and, without replacements, there will be no board. The requirement according to the bylaws is a minimum of 11 board members. Many board members started out willing to "try" the position, attended a few meetings, and then found the place where they could contribute. There is so much more that Second Wind could do, but without willing volunteers, these projects remain merely ideas.

continued on next page

President's Noted continued

This column has focused on the state of Second Wind, but this organization is nothing without you. We appreciate all of you for your membership, your faith in the board's work, and your belief in a strong future. You are the reason that the organization is secure currently. The number of successful transplants is increasing each year and we have more members now with honorary memberships (transplanted more than 20 years ago) than at any other time. We expect this longevity trend to continue.

We want you to care for yourself and your caregivers. Second Wind is here to help you with that job. It is the rare person who is not the caregiver at some point in life. Be sure to acknowledge how important others have been in your life. Do not hesitate to ask for help. If there is something you do not like here, contact a director and be part of the change!

May 2020 be the start of a wonderful year for you, your family and Second Wind—your organization!

Jane M. Kurz
President



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Survival Statistics

By Damian Neuberger, Ph.D., Second Wind Board of Directors

When I celebrated the 22nd anniversary of my lung transplant and my 8th kidney transplant anniversary on October 19th 2019, I decided to find out the survival statistics for lung transplant recipients. Over the years I've heard many people ask about the five-year survival rate, something that was also a concern in the beginning of my transplant journey. I had been diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in 1983 and was told that I had on average 2-5 years to live and there was no treatment and no cure: lung transplantation was not yet available. It wasn't until 1996 that I got a bad case of the flu in January, was put on oxygen in June and told to be evaluated for a lung transplant by September. Fortunately, I live close to Loyola University Medical Center, which has a world-renowned transplant program.

I've lost so many lung transplant friends and contemporaries, and I've wondered why I've survived so long. Yes, I was told that I was a great genetic match for my donor or that I won the genetic lottery, and I thought that couldn't be the whole story (but that's a subject for another article).

Having served two years on the UNOS Thoracic Transplant Committee, I learned that lung transplant data is compiled by SRTR, the Scientific Registry of Transplant Recipients and so was able to obtain the survival rates displayed in the table on the opposite page.

The first column starts in 1990 and extends to 2018, the last year for which they have complete data. The second column to the right shows the total number of pediatric and adult lung transplants performed each year. Following that are columns showing the number of recipients still alive after 6 months, 1, 3, 5, 10, 15, 20, and 25 years.

Readers interested in the percentage survival for a time interval can divide the number of survivors by the number of transplants performed that year and multiply by 100. For example, in 1990, 254 transplants were performed and after 6 months 192 recipients were still alive. Dividing 192 by 254 x 100 produces a 75.6% survival rate. Comparing that to 2018 (2393/2562x100 = 93.4%) shows that after 28 years the 6-month survival rate improved by 17.8%. Similar comparisons can be calculated for each period in the table.

Lung Transplant Recipients and Survivors

Post Transplant: 1990-2018

(Source: Scientific Registry of Transplant Recipients)

“Transplants” = number of lung transplants in each year (adults & pediatrics)

“Time” = number of surviving recipients at each interval post transplant

Year	Transplants	Time							
		6 months	1 year	3 years	5 years	10 years	15 years	20 years	25 years
1990	254	192	180	137	104	57	32	17	11
1991	452	333	308	227	171	96	58	33	20
1992	583	446	402	309	233	123	79	54	43
1993	720	583	540	431	338	179	94	53	36
1994	779	634	579	449	358	175	93	60	46
1995	917	750	699	530	405	198	109	66	.
1996	830	645	586	439	352	194	106	63	.
1997	973	778	728	568	446	246	144	86	.
1998	887	712	661	504	395	228	130	81	.
1999	915	747	687	534	423	233	131	83	.
2000	989	823	756	605	487	274	164	.	.
2001	1061	897	823	646	510	296	172	.	.
2002	1062	912	857	706	572	322	174	.	.
2003	1099	966	908	735	600	346	214	.	.
2004	1197	1074	1010	803	642	377	228	.	.
2005	1440	1253	1182	934	769	479	.	.	.
2006	1432	1266	1202	968	792	454	.	.	.
2007	1496	1311	1213	947	770	449	.	.	.
2008	1505	1333	1249	996	802	461	.	.	.
2009	1689	1504	1411	1133	936	585	.	.	.
2010	1811	1625	1540	1209	981
2011	1848	1664	1560	1254	1004
2012	1782	1620	1546	1240	1029
2013	1945	1790	1697	1394	1156
2014	1949	1779	1672	1369	1187
2015	2072	1922	1837	1520
2016	2345	2185	2082	1794
2017	2478	2319	2214
2018	2562	2393

Additional Data:

Median Wait Time on Transplant Lists (1/1/13 - 6/1/18) = 3 Months

Number of Patients Added to Wait Lists in 2019 = 2,219

Number of Patients Currently On Wait Lists = 1,468

It's Amazing What You Can Do With Lungs that Work!

By Eric Harned, Double Lung Transplant Recipient

My name is Eric Harned and my life changed the winter of 2006 when a fall of nearly 20 feet from a ladder resting on the peak of my garage roof while hanging Christmas lights opened my eyes to a yet undetected lung disease called Bronchiectasis and Idiopathic Pulmonary Fibrosis. An x-ray and diagnosis that would become my enemy over the next 8 years and force me to leave an active lifestyle, coaching and umpiring baseball to one of a sedentary stay on the couch, oxygen 24/7 and a life not worth living. Simply stated, my health declined at a rapid pace and my declining breathing numbers led to me to the organ wait list – and a most fortunate double lung transplant in December of 2014.

My first 51 years had been all about staying active, trying new things, traveling for work and for pleasure, engaging with my kids, coaching their sports, running etc., but life has a way of throwing you a curve ball from time to time and this was an unhittable pitch. I must admit, I never had **GET A DOUBLE LUNG TRANSPLANT** on my bucket list, but God allowed me the chance to extend my life—he and my donor Rita that is, and for that I will be eternally grateful.

As a person who had never smoked, rarely drank and lived a “clean life” as they say, I never would have guessed that from 2006 to 2014 I would be forced to change my lifestyle, spending regular visits with my Lung Specialist, Dr. James Allen to test my breathing capacity, learning that there was no known cure for what I had and that over time my lungs would continue to further scar and just quit working—cutting my life short. This was terrible news to be told and then share with those that loved me. Little did I know that partway through this 8-year health trial, my wife of 24 years would choose the path of divorce and that I would be forced to raise my kids alone – all the while maintaining a full time job and preparing for the worst health wise.

That WORST actually happened the day after Labor Day, September 2014 as I was putting on my shoes for work. I got a terribly heavy sensation in my chest and I could hardly breathe. I was just able to crawl to the phone and call 911, then crawl to the front door to unlock it and lay in wait for the squad to

arrive—not knowing that my right lung had collapsed, almost on cue, 8 years from my initial diagnosis and in line with my pulmonologist’s best guess as to when things would go terribly wrong.

But my unfortunate story does have a silver lining and I prefer to focus the rest of my words on the positives in my life. After two corrective surgeries on my right lung and 17 days in St. Ann’s hospital, I was sent home on oxygen 24/7 and an official diagnosis that without a lung transplant, I had 4-6 months at best. Believe me, those words—“Get your affairs in order”—really hit me like a freight train and I began to pray that very day that God had a plan, and that I would live to see my two kids graduate from high school and college and get married, and that I would return to umpiring baseball—something I loved. But at that moment in time it seemed like wishful thinking at best.

Fast forward through several months of physical testing to insure I was strong enough to withstand the transplant surgery. Likewise several meetings with hospital personnel, my pastor and church elders about in-home care as a single man with no spouse to care for me after my potential transplant, and I officially became listed on December 18, 2014. I was now a potential double lung transplant candidate—not knowing if the call with new lungs would beat the call from God, calling me home. Being 38% Irish must have played in my favor, as a **mere three days later**, on a sunny but brisk Sunday morning, I got the call with the news they found a match and I was about to be transplanted. I was whisked by an elder of my church to OSU Wexner Medical Center to get my new lungs. I was scared to death and rejoicing in the same breath. No pun intended.

A lot of things rush through your head amidst the ride to the hospital and the preparation for surgery, not to mention the hours of waiting for everything to come together. I was officially put under just past midnight on December 22nd and 8 ½ hours later I awoke to find a tube down my throat, 7 tubes coming out of my abdomen, wires and IV’s coming from numerous parts of my body and my hands strapped to the bed. But I was alive! The surgeons told me things went very well



apart from challenges getting the scarred lungs out, but all in all things looked promising. It was at that time I looked to the sky and thanked my God for my second chance and immediately I began to realize that someone else had to lose their life for me to be in this place.

Simply put, things like this don't happen to everyone. Many people die waiting for the call, some die on the table and others die soon after or years later when rejection sets in and the body decides it has had enough. Looking back I believe myself to be a true miracle—a success story and a person who now shares his story with all who will listen. I speak in support of organ donation at area high schools, neighborhood events, medical events and wherever two or more are gathered as the Bible says. My blessings far outweigh the struggles, and the 17 days I spent at OSU Wexner Medical after my transplant were not easy, but the doctors and nurses who treated me helped set my mind in motion to just how fortunate I was and how my life could return to normal or even better if I stayed the course, followed the rules, took my medicines and did what I was told, and boy have I.

As I write this article for Second Wind, I just celebrated my 5-year anniversary of my transplant. Not only am I a Board Member of Second Wind, I am also an Ambassador Speaker for Lifeline of Ohio, the organization that helped to orchestrate my transplant and the transfer of ownership, if you will, of

“I...thanked my God for my second chance and...immediately realized that someone else had to lose their life for me to be in this place.”

my two lungs from my miraculous and loving donor Rita from Vermont to this guy who promised God that if I got a second chance I would never waste a day—living every day to the fullest. That promise was made with great intentions and has been kept without fail.

In summary I have been blessed to see my son and daughter graduate from college in the past 5 years, and anxious to see my son get married this spring. I returned to umpiring baseball after a year off recuperating, and over the past 4 years I have averaged nearly 100 games a season. I have likewise gotten my license to referee basketball and this will be my second season sprinting up and down the hardwood—once again



made possible by my donor Rita. I have likewise completed upwards of ten 5K Walks/Runs for various local causes, and most importantly, I have met a great lady who was not scared away by my gross chest scar and awareness of my transplant. We are currently engaged and I have been given a second chance at love to go along with my second chance at life. Did I say I was Irish?

Simply stated, I know that I am here for a greater purpose and I remain a huge believer in organ donation. My heart goes out to those of you who have lost a loved one waiting for a transplant, but I raise my glass to each of you who have been given a second chance thanks to transplantation. My advice is the adage I live by—don't take a day for granted and don't leave an ounce of gas in your personal tank at the end of the day—LIVE LIFE TO THE FULLEST, cherish your blessings and don't forget to recognize the sacrifices of others—most importantly your donor. Thank you Rita and family, as I'm here today because of a sacrifice that you made.

*Blessings to all,
Eric Harned*

Double Lung Transplant recipient at OSU Wexner Medical

Calling All Poets!



To all the frustrated authors out there, we say it's about time you shared your work with the world! To accomplish this, and in honor of Second Wind's upcoming 25th Anniversary, we're putting together a chapbook of poetry to be published later this spring. So far as we know there are no poetry books available about lung transplantation.

Submissions are due by Monday, March 2, 2020 and should be sent via email to Jane Kurz at kurz@lasalle.edu.

Now, you might THINK you're not a poet, but anyone with a story to tell, a thought or feelings to share can find a way to put them into words. Remember that what's important isn't so much the quality of the writing as it is the honesty of expression, and the opportunity to share your thoughts with those of us who've experienced many of the same challenges.

The types of poetry we're thinking about include:

- Haku
- Sonnets
- Parody
- Limericks
- Free Verse
- Misc. Rhyme Schemes

And in terms of subject matter, you might consider one of these topics:

- Poems about medications & equipment
- Poems about waiting for or getting a transplant
- Poems about life post-transplant
- Poems from spouses, parents, children and/or caregivers as their part of the journey
- Poems from nurses and transplant coordinators
- Poems about organ donation

To help you get started, we can share definitions of the various types of poetry, including examples. If you'd like a copy, or have any questions about the project, send Jane an email at the above address.

Now get to your desk and start writing!



Financial Assistance Program

Eight Years & Counting

On November 2, 2011 the Second Wind Board of Directors voted to create a Financial Assistance Program (FAP) as a way to provide limited financial assistance to members of Second Wind who are lung transplant patients. The program helps pay for the many medical and non-medical expenses incurred by transplant patients that are not covered by insurance. The very first grant was issued in early 2012.

Now, as the program enters its ninth year of existence, the FAP has received and processed nearly 150 applications and awarded grants totaling more than \$60,000.

The program is staffed by a committee of volunteers from the Second Wind Board who obtain verification of the applicant's transplant status, income and level of need, and then make a recommendation for approval/disapproval to the full committee.

Note that grants are issued via third-party payments and that no direct cash grants are issued to applicants. Also, the FAP has specific dollar limits and a formal application process that must be followed in order to determine a transplant patient's eligibility. You can learn more about these requirements by going to our website: www.2ndwind.org and clicking on "Financial Aid" at the bottom of the home page.

Funding Issues Threaten Pulmonary Rehab Programs

Pulmonary Rehabilitation Programs have been shown to significantly improve the quality of life of those dealing with dyspnea (shortness of breath). Unfortunately, changes in how health care is funded in the United States are putting such programs in danger.

As reported in The Buffalo News, the Pulmonary Rehab Program operated by Kenmore Mercy Hospital, the last known free-standing program in Western New York, is one of those programs that will soon close as a result of financial pressures.

Pulmonary Rehab is covered by Medicare and other major insurers, but only for a limited period, and only when provided as a follow-up to hospitalization or a surgical procedure. There is no coverage for programs that work with people with COPD and other lung issues on a continuing basis to maintain their ability to perform everyday tasks.

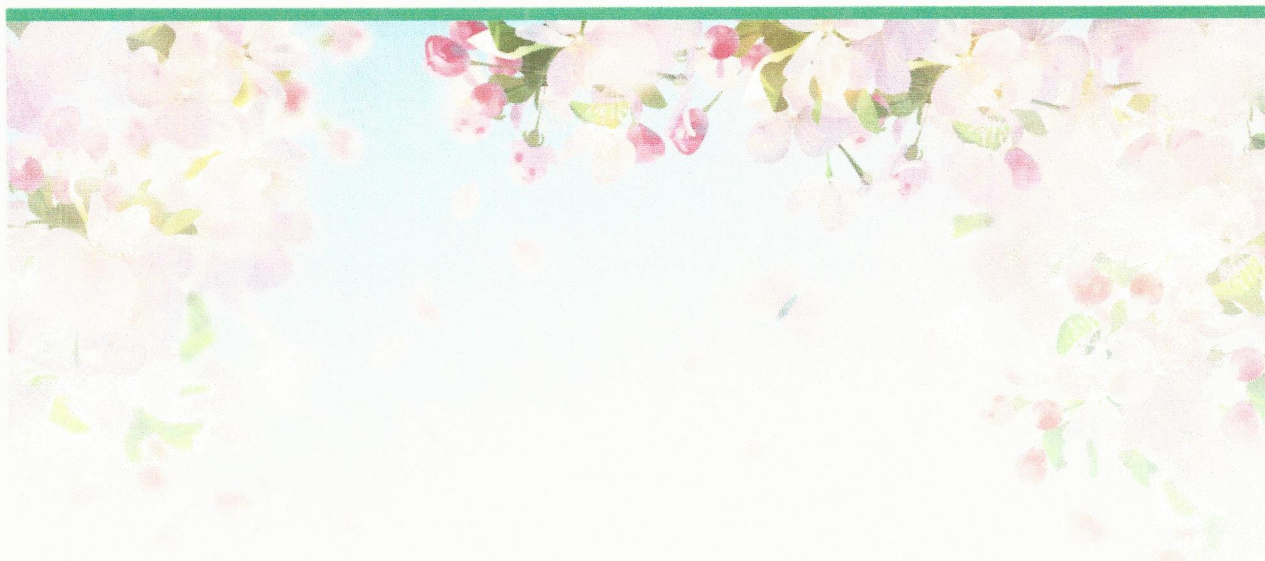
The Kenmore Mercy program costs \$6 per session, and at that price participants can afford to attend 2 – 3 sessions per week. However, the hospital's actual costs are \$25 per session, and it has been covering the difference through payments received for other hospital services. As reimbursement rates for these other services decline it has become impossible for them to continue to subsidize a program whose value is well known.

Here is but one more example of a health care system that prioritizes treatment over prevention, despite the proven cost effectiveness of programs that focus on keeping people well.

Editor's Notes

- When I was first contemplating a lung transplant I often heard that the average survival rate was a sobering 50% after 5 years. The current reality, as outlined in Dr. Damian Neuberger's article on page 4 of this issue, shows that there's been important progress in this statistic over the past twenty years. Be sure to check it out.
- Two new members, Melissa Burke and Ruth Magnus, were elected to the Second Wind Board of Directors at our January 14th meeting. You may recall the story in our last issue that described Ruth's valiant struggle to recover from problems with her transplant. As for Melissa, you'll learn more about her involvement with the transplant community in the upcoming May issue. The Board is pleased to welcome them aboard.
- Please be aware that, due to a technical problem, we had to manually update our mailing list for this issue. If you are aware of anyone who should've received a copy but didn't, send an email to me at phenry2ndwind@gmail.com and I'll be sure they get one.
- We are always looking for contributions and feedback from our readers. If you have a personal story to tell, a recommendation for a topic we should cover, or a reaction to something you've read here, please email me at phenry2ndwind@gmail.com.

Patrick Henry
Editor



The Loss of a Mentor and Friend

It is with great sadness that we report that the lung transplant community lost one of its most giving and caring volunteers on November 14, 2019, when Kathryn Merritt Flynn passed away.

Kathryn was an Honorary Member of Second Wind and a past President and Vice President of the Board of Directors. Kathryn joined Second Wind on May 9, 1998 and quickly took on the responsibilities of an Officer of the Board.

Kathryn grew up with a father who smoked. Like many of us, she began smoking at the age of 13, when she would smoke one or two cigarettes per day. Eventually she increased to one to two packs per day and breathing became a serious problem. In 1987 her physician put her on oxygen 24/7, suggested exercises, and informed Kathryn her prognosis was two to eight years to live without a lung transplant. Kathryn continued to work full-time for seven years as a laboratory research technician while on oxygen. Finally, she had to retire on disability.

During this time, Kathryn and her husband, Richard Merritt, welcomed a daughter, Sarah into their lives. Kathryn has said that her daughter was her lifeline because her husband was a wreck thinking of losing her.

In the Fall of 1994 Kathryn was listed for a transplant at Duke Medical University and on March 25, 1996 she received a bi-lateral lung transplant for Pulmonary Langerhans Cell Histiocytosis. Two short years after her transplant, Kathryn joined Second Wind's Board.

During her tenure on the Board, Kathryn monitored and mentored those waiting for a transplant or who had received a lung transplant on Second Wind's Email Support Group. She also helped with the 800 Help Line and the Peer Support

Program. Kathryn was the type of Board Member who, when you asked during a meeting if someone could volunteer to help an individual who had called in, she always agreed to do all that she could.

After 9/11 we were getting several inquiries from those who were hurt during the rescue efforts in New York. Kathryn researched this problem and wrote a position paper for Second Wind.

After her transplant, she didn't rush back to work but enjoyed her family, volunteering at her daughter's school, for Carolina Donor Services and for Second Wind. She competed in three transplant games in swimming and traveled with her family. Kathryn went back to school and received a Master's in special education and taught deaf children for six years.

Unfortunately, Kathryn lost her husband in 2013 and couldn't celebrate her 18th through her 23rd transplant anniversaries with him.

She rejoiced in seeing her daughter, Sarah Merritt, marry Andy Dolina in September 2017 in a formal ceremony and reception in North Carolina. It was an honor and a privilege to know Kathryn and to work with her over the years.

My prayer is that she is now with Richard in Paradise. May God keep her in His tender loving care and grant her peace.

Cheryl A. Keeler
Past President of Second Wind

Indoor Air Quality For Clean Breathing

By Jennifer Holly

Doctors have long theorized a link between lung transplant rejection rates and air pollution, and according to one study, indoor air pollution can be deadlier than outside. Thus it's more important than ever for lung transplant patients to prioritize the quality of the air in their homes.

Technology that can improve the home's air quality

Ultraviolet air purifiers can be attached to the inside of an air conditioner's outdoor air handler via a strong magnet. The device shines a light that kills germs in the evaporator or induction coil. This prevents mold growth caused by condensation and kills organisms such as mold, mildew, viruses, dust mites, and bacteria by damaging their genetic structure. The device can help to reduce rejection rates for lung transplant patients caused by any of these common pollutants.

Air purifiers are also a good option as they contain filters that capture contaminants, including some viruses and bacteria. Again, these can be connected to a HVAC system or a portable system can be used for one room or area of the home. Some systems contain electrical charges that kill the contaminants, as well as catch them.

Keep smoke out of the home

There are so many things that contribute to indoor air pollution that it can feel overwhelming to know where to start. Small and fairly obvious changes can make a big difference though. Anyone in the home that smokes should do so outdoors only as even secondhand smoke has detrimental effects on indoor air quality, especially for lung transplant patients. Additionally, ditching wood-burning stoves and fireplaces for electric or natural gas options would prevent smells, smoke clouds, carcinogenic chemicals, carbon monoxide, nitrogen, and fine particulates from burning into the air.

Cleaning the home could be harmful to health

A clean home can be key to improving the quality of indoor air, but it can depend on what's being used to clean with. Regular vacuuming and dusting can help to improve indoor air quality. However, commercial cleaning products often contain a large amount of chemicals that have been linked to health issues as they pollute the air. Even products like air fresheners, which merely add more chemicals and other pollutants to the room as they mask, rather than eliminate odors, can be a source of pollution.

Try switching to traditional cleaning methods that don't contain harmful ingredients. Common household items like baking soda, lemons, vinegar and just plain water are all effective for cleaning the majority of things around the home, with the added benefit that they won't increase the chance of organ rejection or failure.

To summarize: indoor air quality is commonly overlooked as air pollution is all too often associated with car exhaust fumes, smoke coming from huge factories, and other things outside of the home. However, indoor air pollution can be worse than outside, which is why it's essential for lung transplant patients to look at their home pollution levels and work to improve it.

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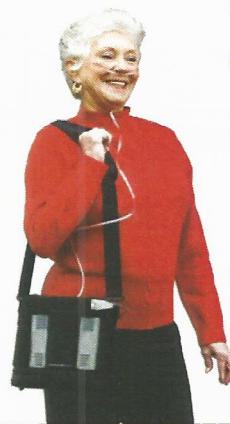
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DONATIONS

GENERAL FUND

Kathryn Bryan
Dr. Marie Budev
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Elena Kahn
John McGill
Ernest Pemberton
Alan Schwenck
Chuck Schuele
Margaret Seanor
Edward Vasbinder – In Honor of Patrick Henry

MEMBERSHIP FUND

Donald Gwynn
Jane Kurz
Mickey McCabe
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Fred Walker

FINANCIAL ASSISTANCE FUND

Prairie Dell Presbyterian Church
Mary Kara
Madelyn LoPresti – In Honor of Frank Shields
Scott Lange – In Honor of Frank Shields
James Lemanski
Mickey McCabe
Garry Nichols
Chuck Schuele
Thomas Staroba
Fred Walker
Gail Weadon

Donations In Memory of...

Tom O'Leary
Charlene O'Leary

Kathryn Fynn
Rhonda Jatta
Charles Fiore

We would also like to thank those confidential members who made a donation. During the months of September through December, 2019 we received two donations from members who previously asked to be listed as "confidential". Thus, we cannot share your information with anyone unless we have your written permission to do so. We thank all of you for your generous donations to Second Wind Lung Transplant Association, Inc.

COPD Foundation

Patient Powered Research Network

The COPD Foundation is a not-for-profit organization whose mission is to prevent and cure COPD (Chronic Obstructive Pulmonary Disease) and to improve the lives of all people affected by this disease.

COPD is a preventable and treatable disease. The COPD Foundation has been established to speed innovations which will make treatments more effective and affordable, undertake initiatives that result in expanded services for COPD patients, and improve the lives of patients with COPD and related disorders through research and education that will lead to prevention and someday a cure for this disease.

COPD Patient Powered Research Network (COPDPPRN)

In furtherance of this goal the foundation is developing a network of over 75,000 COPD patients or individuals at risk who have agreed to share their health information and the impact the disease has had on their lives. A secure database, operated and governed by patients and their partners, will store this information to be used for research.

Joining the COPD PPRN involves filling out a brief survey. Then, at some point in the future, you could be contacted to take part in clinical trials or studies. Participation is always voluntary.

Anyone over the age of 18 who responds "yes" to at least one of the following is eligible:

- Have been told by a doctor that you have COPD.
- Have a family history of respiratory disease.
- Is a current or former smoker.
- Symptomatic of respiratory disease (including but not limited to coughing, shortness of breath or wheezing).
- Have had a possible or known environmental/occupational exposure that may put you at risk for a respiratory disease, including but not limited to second hand smoke, indoor and/or outdoor air pollution.

If you are interested in participating in this effort, or have any questions about the COPDPPRN, you can contact the study coordinator at 1-866-731-COPD (2673), ext. 396 or email COPDPPRN@COPDFoundation.org.



Tattoo or Not Tattoo? (That is the Question)

A recent discussion on the Second Wind Message Board revolved around the question of whether or not it's safe for immune suppressed people to acquire tattoos. While there have apparently been no definitive studies on the issue, a recent article in "The Guardian" described a case in which a lung-transplanted woman experienced a severe reaction after receiving a tattoo on her thigh.

A week after receiving the tattoo her knee was swollen and the pain radiating from the quad area was severe enough to lead her to seek treatment. Multiple tests verified the muscle was inflamed, but could not pinpoint the source. Doctors made a reasonable presumption that the fresh tattoo, combined with her suppressed immune system, was the cause of her problem. It took a year's worth of physiotherapy before she began to feel better.

It's important to note that this could be a very rare case; also, that the same woman had received a tattoo on her other leg before being transplanted, one that gave her no trouble.

As always, transplant patients are encouraged to consult with their medical team before making any decisions, which could affect their health, including whether or not to acquire a new tattoo.

Transplant Anniversaries

NOVEMBER 2019

<i>Name</i>	<i>Transplant Date</i>	<i>Years</i>
Carolyn Blaylock	11-5-03	16
Cathy Cuenin	11-9-04	15
Chuck Schuele	11-20-08	11
Susan Sweeney	11-2-14	5

DECEMBER 2019

<i>Name</i>	<i>Transplant Date</i>	<i>Years</i>
Betsy Cichon	12-16-04	15
Gage Georgeff	12-14-09	6
Eric Harned	12-22-14	5
Dennis Koppes	12-1-18	1
Janice Laidlaw	12-19-17	2
John McGill	12-5-12	7
Etta Milton	12-1-17	2
C. Lorenzo Pope	12-4-17	2
Fred Walker	12-15-06	13

JANUARY 2020

<i>Name</i>	<i>Transplant Date</i>	<i>Years</i>
Karen Couture	1-21-96	23
Holly Hahn-Baker	1-3-98	21
Dan Griggs	1-11-16	3
Blaine Lesnik	1-8-15	4
Brian Puhalsky	1-30-17	2
Jeanne Roberts	1-1-17	2
Michael Thomas	1-16-12	7
Cynthia Zimmer	1-20-18	1



Support Groups & Events Calendar

Lung Transplant Support Groups

Dover Campus, St. Clare's Health System

400 West Blackwell Street, Dover (Morris County), NJ
For information, call (732) 412-7330

Cincinnati Support Group

Second Thursday of each month at 6:30pm, hosted at the home of Robert and Cynthia Lohstroh: 4120 Beamer Ct., Cincinnati, OH 45246. Phone: (513) 752-0451.

Covers Cincinnati, Dayton, and Northern Kentucky.

St. Louis Second Wind Lung Transplant Association

Second Wind of St. Louis is now available on Facebook by searching that name.

Second Sunday of each month, 2pm at Chris' Pancake and Dining, 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 Group

Shands Cancer Hospital, South Tower, 5th Floor 1515 SW Archer Rd., Gainesville, FL 32610 Contact: Micki Luck, nodurn@shands.ufl.edu Phone: (352) 519-7545

University of Washington Medical Center Seattle, WA

Pre- and post-transplant Support Group

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

Contact person: Angela Wagner, MSW
(206) 598-2676; 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 – 1:00pm

Mercy Conference Room

Contact: Kathy Lam, LCSW
Kathy.Lam@DignityHealth.org ,Phone: (602) 406-7009

University of Chicago Medical Center

Lung Transplant Support Group for transplant recipients and those who are listed. Third Wednesday of every month, 5-6:30 pm. Center for Care and Discovery (CCD),

7th Floor Conf. Rm. 7710

5700 S. Drexel Ave., Chicago, IL 60637

Contact: Fran Hammon, LCSW
frances.hammon@uchospitals.edu or call (773) 702-4608
Pager 6720

continued on next page

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 September, 2019 through December, 2019 we had 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.

Jeffrey Alvarado

Robert Bock

Melissa Burke

Taylin Cook

Robert Dokes

Paul Enslin

Timothy Groger

Daryl Long

David Lymangrover

Mary Narkevicius

Robert Ogando

Matthew Pasick

Daryll Stuffco

Edward Vasbinder

Angela Wagner

Kale Willis

Membership Renewals

In addition to the names listed below, during the months of September, 2019 through December, 2019 we had renewals from eight 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.

Kathryn Bryan

Dr. Marie Budev

Donald Gwynn

Eric Harned

Denise Jacobs

Edward Kuhn

Jane Kurz

Ruth Magnus

Julie Martin

Etta Milton

Garry Nichols

Erin Odell

Lois Peddigree

Ernest Pemberton

Lisa Potter

Margaret Seanor

Ed Smiley

Fred Walker

Gail Weadon