

Just Put One Foot in Front of the Other

By Margaret E. Seanor – Double Lung Transplant Recipient - June 19, 2018

I believe I started training to hike Mt. Elbert, the highest peak in Colorado, days after my transplant.

I received my life-saving gift—twenty-year old male lungs—on June 19, 2018. I think about the young man who lost his life and the family who so generously gave me life. My sons have a mother, my grandsons have a grandmother, and my brother and sister still have me.

My team told me taking my medications and exercising would keep me alive. I listened.

The first challenge was walking circles around the nurses' station, which was an amazing experience because I could hardly walk across my living room prior to my transplant. My son, Arnold, walked behind me, encouraging me, pushing me to my limit. I can still hear him saying: "Move it, move it, move it!" I turned and looked at him and said: "Who raised you?"

When I returned home, my daughter-in-law, Tammy, patiently walked with me around the neighborhood, walking the same path, over and over.

I bought a bicycle and started riding trails close to home.

My son, Harlan, challenged me to hike Red Hill. To get to the top is a one-mile hike with a 950-foot ascent. A more strenuous hike than any other I had attempted. Not knowing the trails on Red Hill, I picked the most difficult, Ruthy's Run. I was alone and scared. I had no idea what I was doing. I just did it and I made it to the top.

My friend, Electro, became my best hiking buddy. We hiked in all kinds of weather, trying more and more difficult trails. When I slipped and fell in the snow, I laughed, and my buddy helped me up and encouraged me to go on.

I set my sights on hiking a 14er, which is a mountain greater than 14,000 feet. Harlan said he *might* consider taking me if I could walk fifteen miles.

I decided to walk ten miles. It was tough, but not that tough, so I decided to walk twenty miles. After eleven miles it started to rain. Harlan and Tammy called to check on me and offered to pick me up. I was determined to finish. I did. I was wet, cold, tired, had blisters on my feet and was delighted.

I started cross-country skiing and discovered it is the best workout and another new, fun challenge.

I made sure I hiked several times a week, all through the year, looking for more and more difficult hikes. I found more and more friends willing to hike with me.



L-R: Harlan, Margaret (the Author), Electro, Arnold

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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.

Articles printed in this newsletter are for general information only and are 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 circumstances. It is your responsibility to discuss any information herein with your physician to determine whether it is beneficial or deleterious to your health.

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.

To submit an article for publication in *AirWays*, send an MS Word document as an attachment to: phency2ndwind@gmail.com.

To join or change your address please contact Second Wind via email to phency2ndwind@gmail.com.

Comments or suggestions? Email us at airwaysfeedback@gmail.com

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President's Notes

Tom Nate, President

Second Wind Lung Transplant Association, Inc.



The fall season is officially upon us and as we all know, cold and flu season comes with it and, of course, Covid 19 is still with us and projected to possibly have some “flair ups” in the colder areas of the country. I know that we as transplant patients and lung patients don’t have to be reminded of taking extra care during the cold and flu season

to protect against catching these. So just a quick reminder to have a plan of action with your transplant team and/ or doctor of steps you will take if you start feeling symptoms.

Since we postponed our last issue of *Airways* due to administrative situations, I did not get to officially recognize and welcome our newest Second Wind Board Members. Tracey Linebarger was elected to our Second Wind Board in August and then in September we elected Pat Libens to the Board. Both are lung transplant recipients and both bring a wide range of experience and enthusiasm to our group. We are so grateful for their willingness to serve Second Wind and our members.

I want to remind you of the existence of our Email Support Group (ESG), which is open to all Second Wind members. The ESG provides a forum for questions seeking answers from each of us based on our experiences in the lung transplant journey. While we don’t want group members to give medical advice (reserving that for your doctors and transplant teams) there is still much we can all learn from each other based on own journey. Things change so fast in the worlds of technology, medications and procedures, that we may be dealing with an issue health-wise that we think there is no solution or treatment for, yet there may be answers that group members can share based on all of our collective experiences.

I hope to generate some great discussion topics, and look forward to your participation in the discussions. If not already a member of the ESG, drop me a line at tnate1254@gmail.com and I’ll set you up.

Finally, September is always a very special month for me as it is the month I had my second bilateral lung transplant surgery. Each year that I pass that anniversary date, the more meaningful and thankful I become. This year is my 12th anniversary of my second surgery and I celebrated it by making sure I celebrated my caregiver, my wife Irma, who,

even with doctors telling her I would not live, stood firm in her belief and faith that I would survive. I celebrated the joy of breathing easy, and she celebrated with a dozen roses.

In closing, I came across a little note online, author unknown and thought it appropriate to share with all of you.

“Transplantation is an amazing journey that tests the limits of human strength and courage. It requires commitment and faith as well as mental, emotional and physical endurance. If you can handle transplantation, you can conquer anything you set your mind to. It is one of life’s greatest challenges, and among the rewards is LIFE itself.”

Editors' Notes

- This issue of *AirWays* contains stories from lung transplant patients who describe how they dealt with personal challenges related to their transplant. Our thanks to Peggie Seanor and Ruth Magnus for sharing their stories. We encourage you to consider how your experience might help others confronting similar challenges. Please email us at airwaysfeedback@gmail.com for more information on how you could participate.
- We also encourage your suggestions about how we can make *AirWays* better. Send any comments you may have to the same email address listed above.
- We want to thank our Board Treasurer, Sarah Ridder, and our volunteer data base administrator, Mark Henry, for their help in getting every issue of *AirWays* into your hands. We couldn’t do it without them.
- Finally, we wish to recognize the recent passing of Robin Evenhouse, who, with her brother, Peter, built and operate Evenhouse Printing, the company responsible for the design, layout and printing of this newsletter. Robin was a dynamic businesswoman and leader, and will be greatly missed by all who knew her. Our condolences to her partner, family and all the staff at Evenhouse Printing.

Renae Woods & Patrick Henry, Co-Editors

My sons, Arnold and Harlan, who are experienced at hiking 14ers and paramedics, offered to take me to the summit of Mt. Elbert, which is 14,438 feet. My best hiking buddy, Electro joined us.

The night before the hike, on August 3rd, 2022, we camped out, close to the trailhead. Harlan was up at 3:20 making coffee. Breakfast was at 3:30. Our camp was torn down by 4:00. We all jumped into Arnold's truck and were at the trail head at 4:30. With headlamps on, we started up the mountain. Our starting point was at 10,000 feet.

"I HAD NEVER HIKE IN THE DARK, COOL HOURS OF THE MORNING. IT WAS MAGICAL."

I had never hiked in the dark, cool hours of the morning. It was magical. The only sound was the crunching of our steps. It didn't take long before we were watching the sun come up. What a beautiful sight.

I was totally focused on my pace and immediately felt the constant incline. I wasn't talking like the others. I kept all of my focus on keeping a constant pace and conserving energy by not talking.

As we ascended, I wanted to take breaks, but my boys told me to keep going as it takes more energy to start up after a stop. "Just keep going, one step in front of the other, no matter how slow you go," they said. I felt inadequate hiking at such a slow pace, knowing my boys could be jogging up the mountain. I appreciated their patience and the gift of their time—the greatest of all gifts my sons could give me.

Hiking through the trees was cool, peaceful and a time to reflect. When we hit the tree line, I could feel a definite change in my body. I felt sluggish. I was telling my legs to keep moving, but I was definitely slowing down.

Arnold announced when we hit 13,000 feet. Arnold, Harlan and Electro looked delighted. All I could say is: "This is hard. Really, really hard." Arnold detected I was holding back tears, and said, with a big smile on his face, "It's all in the attitude. You can do this." Electro said: "You gotta keep going. We have to get to the summit by 10:30 or we'll have to turn back."

Harlan was constantly available to give me water and snacks because he was carrying my pack. He was walking closely behind me, and ever reminding me to keep up the pace so we could get to the top before the afternoon storms, which bring dangerous lightning. My support team anticipated all my physical and mental needs.

There were no trees, no bushes, no greenery of any sort. Just rocks and more rocks. Rock stairs and slippery rock. The views became increasingly breathtaking. Some clouds appeared in the sky. I glanced up at times, but mainly kept my focus on the pace and watching to make sure my next step was solid so I wouldn't slip or trip. My body felt heavy and unwilling to respond, but I kept walking, slower and slower.

We hit 14,000 feet. I looked at the three of them and stated: "I said I would hike up to 14,000 feet, and I've done it." The last 438 feet looked absolutely impossible. I saw people at the summit and people slowly approaching the summit. Some were coming down.

Electro said: "You will never forgive yourself if you don't hike up the last 438 feet." I agreed. Arnold and Harlan encouraged me to get going to the top because I was wasting time and our turnaround time of 10:30 was quickly approaching.

I put one foot in front of the other. I wasn't thinking about where I was, what I was doing, how long it would take to get to the summit, or if my body needed water or food. My whole focus was picking up one foot, getting it safely planted, picking up the other foot, and on and on until ... we reached the summit!

All three boys were delighted. I was overwhelmed and crying. I could hardly talk. It was absolutely amazing. I have no words to describe how it felt for me to be standing at the top of Mt. Elbert with Arnold, Harlan and Electro. We made it. We were standing at 14,438 feet. All three of these young men put out an amazing amount of planning, effort and patience to hike this hike with me.

Harlan announced we only had ten minutes and needed to head back down. I was filled with joy and my body started responding with more strength on the descent. At last, I had no doubt that I was going to make it to the finish line.

I am so incredibly grateful to them, and simply to be alive!

HELP Line Disconnected

Due to cost and staffing issues the Second Wind 888# HELP line is no longer in service. Recent experience shows that the line was receiving only a half-dozen or so calls each month, so the Board decided it no longer made sense to continue funding it.

You can still reach any member of the Second Wind Board of Directors by going to our website (2ndwind.org) and clicking on "Contact Us" at the bottom left side of the Home page. You should hear back from us within 24 hours.

Home-Based Pulmonary Rehab

Pulmonary rehabilitation (PR) is designed to prevent and/or delay functional decline in patients with respiratory failure. Programs focus on exercises and breathing techniques that improve balance, gait, strength, and respiratory exchange. PR has proven to be highly effective in improving the entire health status of patients with COPD. In studies of patients with moderate to severe COPD receiving PR, functional capacity improved at very close to the same level as independence in daily living activities. Improved functional capacity also directly affected mood and mental status. Patients showed and reported fewer symptoms of anxiety and depression as functional capacity improved.

It is well known that PR is very beneficial in improving overall health in all patients. However, very frail individuals with chronic respiratory failure are likely to have problems with attendance and completion of the program. Home based PR may be more beneficial for these individuals, as barriers affecting attendance would be eliminated. Home-based PR for 8 weeks using interventions tailored to each individual's abilities and needs is an attractive approach for the frail patient who has problems traveling. 80% of patients who were frail prior to the home program improved their frailty status after 8 weeks. By 8 months after the patient was discharged and continued exercises at home, symptoms of depression were significantly improved as well.

Lungs In A Box

Doctors at Northwestern Medicine in Chicago have developed a unique procedure in which lungs are taken out of the human body, put on a platform hooked up to a machine simulating the breathing of a human body. The lungs can be seen inflating and deflating outside the chest, providing a better view for doctors examining the organs for transplant. The procedure is nicknamed "lungs in a box." With lung perfusion in the lungs in a box, organs can be left out of the body for much longer giving doctors more time to examine and repair. Tiny tears and many other defects are more visible when inflation/deflation occurs. Since donated lungs last longer with this procedure and repairs can be done more effectively, lungs that were once deemed unfit for transplant can now be utilized, cutting down waiting lists for those in need of a lung transplant.

DONATIONS

Since the COVID pandemic hit in 2020, Second Wind has been waiving all membership dues. We're continuing this practice for the moment, but note that it has had a serious effect on our finances. For that reason we have once more included a Donation Envelope in this issue, and urge those of you who can afford to do so, to consider making a voluntary gift to support our work.

We want to recognize and thank the following individuals who have made a generous donation to support the mission of Second Wind.

In Memory of Cathy Cuenin

Marcia Fort
Bernice Funk Cade
Eric Harned
Sarah Isto
Tom Lane
Victoria Lauglin
Debi Rathbone
George Reifenstein Jr.
Sally Slater
Dan Stroeing
Wayne Vlasak

In Memory of Russ Housman

Hearts for Russ Housman

In Memory of Fredrick Kurz

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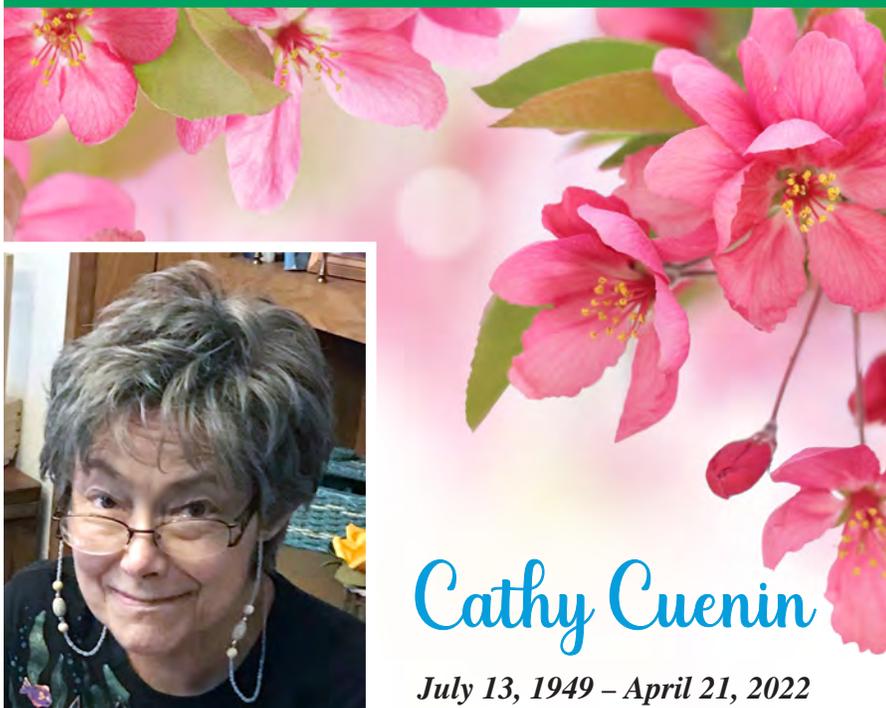
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Cathy Cuenin

July 13, 1949 – April 21, 2022

The world lost an amazing woman, and Second Wind lost a valued member of the Board of Directors when Cathy Cuenin of Suquamish, Washington passed away earlier this spring.

Cathy was a retired nurse, therapist and acupressure practitioner, a poet and memoirist, and a seventeen-year survivor of a double lung transplant.

Born in California, she moved to Alaska in 1974 with her husband, Loren, where they lived on a tugboat. They traveled the waters of Southeast Alaska doing various towing jobs, while Cathy worked as a public health nurse in the villages they visited.

In 1997 Cathy's lung collapsed and she was diagnosed with LAM (Lymphangioleiomyomatosis), a rare condition in which the lung can collapse without warning at any moment. This led to her double lung transplant in 2004.

She wrote about her life and transplant story in a fascinating book, [The Way I Walk, From Tugboat to Transplant](#), which is currently available at Barnes & Noble and other bookstores.

Cathy fulfilled vital roles for Second Wind first as a volunteer covering our HELP line, and then by joining the Board in 2021. As she said, "I enjoy being able to have a long conversation with someone who is frightened by their condition and the thought of transplant...".

In addition to her husband, Loren Gerhard, Cathy is survived by their son AD, his wife Elizabeth and their daughter Clara, her parents, Robert and Virginia Cuenin, siblings Mary Chambers, Judd Cuenin, Carol Mertens, Rob Cuenin, their spouses and many nieces and nephews.

The Board of Directors wish to convey their deepest sympathies to Loren, AD and all the members of Cathy's extended family. She was indeed a unique presence in all our lives.

COVID-19 Remains a Threat

Despite declining numbers, the continuing mutations of the COVID-19 virus mean that it remains a threat in our communities, and is particularly dangerous to lung transplant patients.

It's time to talk with your transplant coordinator, doctor/nurse practitioner, or Primary Care Physician about scheduling another COVID booster (or 5th shot) which also covers the current variants, as well as a first or second dose of Evusheld.

Evusheld is a monoclonal antibody that targets COVID and works with the COVID vaccines for additional response of the immune system. On 6-29-22 the FDA revised the Emergency Use Authorization for Evusheld to recommend repeat dosing at 6 month intervals in transplant patients and other immunocompromised individuals. It was determined that Evusheld antibodies will not last in your body forever, so repeat dosing at 6 month intervals is necessary for ongoing protection. It is recommended that the 5th COVID booster and Evusheld be spaced 2-3 weeks apart.

Note that a release from the FDA dated 10/3/22 states that Evusheld may not be effective against the most recent variants. Nonetheless, the FDA continues to recommend Evusheld as an appropriate option to prevent COVID-19. In combination with other preventative measures like getting vaccinated and boosted as recommended, Evusheld still offers protection against many of the currently circulating variants and may offer protection against future variants.

Also, flu shots are now being administered. All vaccines are very important to immunosuppressed individuals, so diligence in receiving them timely is thought to be to your advantage.

Again, always discuss with your coordinator or doctor/nurse practitioner to determine what is best for your particular situation.

Transplant Anniversaries

MAY 2022

Name	Transplant Date	Years
Rudy Arce	5/25/2019	3
Connie Buchs	5/24/2015	7
Mandy Carrasquillo	5/19/2015	7
Marc Chelap	5/7/2013	9
Maggi Czoty	5/2/2013	9
Fred Harris	5/28/2016	6
Rachelle Ledbetter	5/1/2021	1
Mike Malette	5/12/2021	1
Thomas E Nate	5/3/2007	15
Matthew Pasick	5/6/2019	3
Lori L. Schilling	5/9/2003	19
Justin Stanley	5/24/2019	3
Les Wall	5/16/2018	4
Anna Young	5/25/2021	1

JUNE 2022

Name	Transplant Date	Years
Joseph Aiken	6/17/2020	2
Christopher Bonk	6/3/2021	1
Cassie Buckner	6/19/1998	24
Teffy Chamoun	6/8/2019	3
Brian Conley	6/5/2015	7
John Durham	6/23/2020	2
Douglas Hollifield	6/28/2020	2
Denise Jacobs	6/4/2017	5
Holly Kroeze	6/3/2021	1
Mary Narkevicius	6/10/2010	12
Helen Nichols	6/17/2019	3
Margaret Seanor	6/19/2018	4
Charles Staples	6/22/2002	20
Susan Tate	6/3/2021	1
Paul Woods	6/10/2013	9

JULY 2022

Name	Transplant Date	Years
Catherine Bosnan	7/7/2020	2
Terri Christenson	7/9/2014	8
John Della Jacono	7/19/2019	3
Thomas Hayes	7/17/2018	4
Daniel Kolopajlo	7/4/2019	3
Patrick Libens	7/27/2019	3
Ruth Magnus	7/20/2008	14
Darcy Ode	7/18/2014	8
Michael Pazen	7/9/1999	23
Julianne Pease	7/24/2020	2
Ralph Rhodes	7/21/2021	1
Kayla Shirell	7/10/2021	1
Anita Tracey	7/3/2005	17
Karen Vollten	7/23/2016	6
Ina Williams	7/14/2020	2

AUGUST 2022

Name	Transplant Date	Years
Kandi Bastianelli	8/27/2019	3
William Bostick	8/15/2007	15
Jan Chicoine	8/16/2020	2
Tamara Geunther	8/15/2020	2
Harlan Halvorson	8/24/2006	16
Dave Harris	8/12/2016	6
Patrick Henry	8/25/2015	7
Gwen Herron	8/11/2012	10
Jack Hollenbach	8/3/2007	15
Orlan Holmes	8/2/2002	20
Francesca Magee	8/23/2020	2
Aldo Mancilla	8/13/2010	12
Julie Martin	8/29/2005	17
Ruben Ogando	8/18/2018	4
Michele O'Guinn	8/26/2004	18
Toni Perez	8/15/2021	1
Michelle Takemoto	8/15/2020	2
Chris Towe	8/26/2018	4

SEPTEMBER 2022

Name	Transplant Date	Years
Tim Calkins	9/29/2018	4
Paul Enslin	9/21/2019	3
Kevin Gargan	9/5/2016	6
Linda Grubb	9/17/2021	1
Karina Hallinan	9/13/2019	3
Brian Jenkins	9/2/2009	13
Nancy Lee	9/23/2011	11
Veronica Lobo	9/5/2020	2
Daryl Long	9/4/2019	3
Michael Long	9/26/2019	3
Arapata Albert McKay	9/29/2020	2
John McNamara	9/18/2006	16
Cheree Peirce	9/16/2012	10
Pamela Thorkelson	9/17/2019	3
Lloyd Turner	9/27/2020	2
Carolyn Vega	9/1/2013	9

OCTOBER 2022

Name	Transplant Date	Years
Lotfi Ben Abdallah	10/28/2020	2
John Berti	10/8/2019	3
Beth Davenport	10/20/1995	27
Julia Flatt Cohn	10/5/2020	2
Courtney Harris	10/16/2020	2
Sonia Joseph	10/23/2019	3
David Lischer	10/15/2017	5
Mickey McCabe	10/17/2016	6
Damian Neuberger	10/19/1997	25
Kay Ryan	10/18/2020	2
Alan Schwenck	10/6/2009	13
David Somerville	10/30/2017	5
Charles Vigil	10/28/2018	4
Danette Ward	10/24/2019	3
Jennifer Wilcock	10/6/2019	3
Scott Willoughby	10/26/2017	5

In Memoriam

Second Wind wishes to recognize the recent loss of the following members:

Cathy Cuenin

Transplanted 2004

Susan Tate

Transplanted 2021

Fred Triquet

Transplanted 2010





My Trip To Orlando ...When Mr. COVID Came Along For The Ride

By Ruth Magnus, Second Wind Board of Directors

In February 2020 I was diagnosed with chronic rejection, which was a shock. To make matters worse, in March we went into quarantine because of COVID. It was not an easy time—trying to understand chronic rejection and learning to live with COVID.

We had to adjust to this new lifestyle. After a short while we thought it would be okay to have people visit, sitting apart on the patio. The weather in California is usually pleasant enough

and we managed to get through the winter, and the summer, and the winter again.

In May 2022 my husband Stan's company was holding a conference in Orlando. I had missed a previous trip to Nassau, so this time I said, "Let's do it!" Not only had I been cooped up for so long, but I was hearing about acquaintances who were terribly ill, and some who had died. I decided it was time to start living again, while being as careful and as sensible as possible.

My children were against it and my friends thought I was crazy, but I was determined to go. So, we were off to Florida.

What was I thinking?

This was my first flight since COVID, and the first time staying in a big hotel with over 600 people at the conference. The flight to Orlando went well. I decided to eat on the plane (heaven forbid I should go without a meal!) so I nervously removed my mask and ate quickly.

We arrived at the resort and boy, was it huge!

That night we went out to dinner, just Stan and I. We sat outside in the heat and humidity—the only ones there. By the time our appetizer arrived the weather had changed. It became overcast and windy, and then came the rain. What

were we to do? Give up the rest of our dinner or sit inside? We hadn't sat inside a restaurant since the beginning of COVID! We took the plunge, asking for a table away from anyone else. There was no such thing. We did get one in a corner, near only one other table.

The next few days were filled with activities in the conference, and time sitting at the pool. The dinners were scheduled to take place outside. Unfortunately, the weather was not our friend and it rained all but one of the evenings. This meant we had to join 650 people for dinners in the conference room.

I was really nervous. The first night we sat at a table for two near the entrance—not a good move. Everyone stopped to say hello. I had my mask off because I was eating, and kept putting it back on whenever someone stopped. On off, on off, on off. It seemed hilarious at the time, but wasn't quite so funny later...

On Sunday we left for Tampa to stay at a friend's house. On Tuesday we went touring and it was extremely hot and humid. I was tired, and had no energy. When we got home, I said I felt a little strange. They said that possibly I had heat stroke. I drank some electrolyte water and energy water and plain water! I also wrote to my transplant coordinator explaining how I felt, and she agreed it was heat stroke.

**"THE TRUTH WAS HARD TO ACCEPT—
I TESTED POSITIVE FOR COVID!"**

We had a lovely evening and I thought I had recovered, but the next morning when I awoke, I knew something was wrong. My throat was sore and my head felt heavy. The truth was hard to accept—I tested positive for COVID! My transplant coordinator contacted Tampa General and arranged for me to have an infusion, warning that it couldn't be Paxlovid, which would interfere with my medications.

Luckily, my husband felt fine, and tested negative, but we had to move out of my friend's house. We had previously arranged to meet with another friend's brother. I called him to tell him that we couldn't meet because I had COVID. He said he wasn't feeling well either. After some back and forth he offered to let us stay in his guest house, where we could remain isolated.

continued on next page

My Trip to Orlando...continued

Well, how lucky can one get? The guesthouse overlooked a lake and a swimming pool. And it was stocked with everything we might need.

The next day I had my appointment for my infusion. I hardly felt sick—just a little tired. For the next few days we sat in the shade, went in the pool, and took it very easy. Now THIS, I thought, is the way to quarantine!

When we came home everybody wanted to know how I felt about having gone. I answered that now that I have had a mild version, I was no longer afraid of it. So, in the end, I was actually happy that Mr. COVID had come along on our trip.

Cutting Edge Medicine

By Reneae Woods, Board Member-Second Wind

Lung Snake Robot

Researchers from the University of Leeds (UK), have developed a snakelike robot that can be used to detect and treat pulmonary diseases, including lung cancer. The robot is designed to slither across human lungs into small crevices that would otherwise not be detectable. In cases requiring treatment/repair, robotic care is much less invasive, eliminating risks of surgery. The magnetic tentacle robot is composed of magnetic discs, roughly 2 mm thick and less than a tenth of an inch long. It is about the size of a ballpoint pen tip.

In the future, the snake robot could also be used to more thoroughly examine other organs, such as the human heart, kidney, or pancreas. Dr. Pietro Valdastri, the project's lead researcher and chair of robotics and autonomous systems at the University of Leeds, said in an interview: "My goal...is to find a way to reach as deep as possible inside the human body in the least invasive way as possible."

This is good news! I personally know individuals who received transplanted lungs with a small cancer, or an injury. The defects were not detectable during harvest procurement. The Snake Robot could be more effective examining organs for transplant as well as surgical repair, increasing the transplant survival rate.

Blood Tests Found Reliable in Evaluating Severity of PAH

Pulmonary arterial hypertension (PAH), is a complication causing high blood pressure of the main pulmonary artery from the heart to the lungs. Small pulmonary arteries become progressively narrowed and blocked as well. Symptoms of PAH are chest pain, dyspnea, swollen ankles, and fatigue. In more severe cases, the lungs and heart can be so severely damaged that heart-lung transplantation is required.

PAH can be caused by scarring in the lungs or pulmonary fibrosis. Scarred arteries become thick and stiff making it difficult for blood to flow through, elevating blood pressure in the lungs. The right side of the heart is overworked pumping blood through narrowed, scarred arteries causing enlargement of the right side of the heart. There is a high probability of death in advanced cases due to heart failure. PAH can be genetic with unknown etiology. This condition is rare and affects more women than men with approximately 50,000 people diagnosed in the US, according to the National Institutes of Health (NIH) Genetic and Rare Diseases. There is no cure for the genetic type. It is important that an accurate assessment of severity be established in all cases of PAH. Doctors rely on echocardiography or heart imaging, as well as heart catheters to measure pressures in the lungs. These tests lack reliability.

Researchers at the NIH have found that a simple blood test can be used to monitor severity. DNA fragments are shed in the blood when there is PAH. These fragments, called cell-free DNA are elevated and increase with severity when there is PAH. Having an accurate measurement of severity allows doctors to intervene faster to delay progression of the disease. Cell-free DNA is relatively new and growing in medical uses including early detection of heart and lung transplant rejection, as well as early detection of cancer.

Dr. Michael A Solomon, who is part of the NHLBI Cardiovascular Branch and co-author of NIH Clinical Center said, "Researchers have been searching for a novel, less invasive approach to evaluate PAH severity, disease progression, and response to therapy for more than a decade. These cell-free DNA analyses represent progress toward that goal."



Medicare & Organ Transplants

Expanded Coverage For Kidney Transplant Meds Begins January 1st

A law takes effect on January 1, 2023 which provides lifetime Medicare coverage for immunosuppressive drugs for kidney transplant recipients. Previously, people who were only eligible for Medicare because of their end-stage kidney failure were covered for these vital medications for a maximum of 36 months post-transplant. Now, anyone who meets the following criteria will qualify for lifetime Medicare coverage under Part B for these drugs, regardless of age:

- Received a kidney transplant from a Medicare-approved facility.
- Was eligible for Medicare at the time of their transplant or applied prior to their transplant.
- Does not have Medicaid or other public or private health insurance.

There is a premium associated with this benefit, but the amount has not yet been set.

In order to begin receiving the expanded coverage starting in January, you must sign up by December 31st.

To learn more, contact Social Security at 1-800-772-1213.

Medicare Coverage For Lung Transplant Immunosuppressive Drugs

Medicare covers immunosuppressive drugs for lung transplant recipients if Medicare paid for the transplant. You must have Part A at the time of the transplant, and you must also have Part B at the time you receive these drugs. You would then be responsible for 20% of the Medicare approved amount for the drugs.

Keep in mind that Medicare Part D (drug coverage) will cover the cost of these drugs if Part B doesn't cover them.



Medicare Advantage Plans & Transplant Patients: What You Should Know

We are entering the time of year when Medicare recipients have an opportunity to sign up for Medicare Advantage plans, or change to a new plan. Individuals who are currently on a transplant list, or who anticipate being listed at some time in the future, need to insure that the Advantage Plan they sign up for will cover the cost of their transplant.

While Medicare Part A covers doctors' services for transplant, and generally covers the cost of the surgery itself, some Advantage Plans provide additional coverage.

If you're considering signing up for, or changing to a new Advantage Plan, you need to check with the plan before you join to make sure your doctors, other health care providers, and hospitals are in the plan's network. Also, check to see what the plan's coverage rules are for prior authorizations. Some plans require that you obtain prior authorization for transplant coverage prior to the procedure.

You can find more information on these topics by going to [Medicare.gov](https://www.Medicare.gov).

New Members

The following individuals became members of Second Wind during the period May – October 2022.

We welcome and thank you for your support of our mission.

Laura Garcia Aguinaga	Ashraf Mahomed
Dolores Beattie	Ray Maloy
Kevin Brady	Carol Mitchell
Peter Brown	Marguerite Newhouse
Linda Burban	Darcy Ode
Christine Capriati	Elizabeth Papin
Katherine Carson	Toni Perez
Merilyn Davis	Eugene Prettyman
Danielle Donegan	David Read
Kathleen Dowdle	Dr. Gwenn Rosenberg
Loren Gebhard	John Tracy
Mohammad Hayat	Gregg Walters
Kathryn Horn	Richard Wyatta
Gail Lewis	Alisa Yocum

Membership Renewals

The following individuals renewed their membership in Second Wind during the period May – October 2022.
We thank you for your continued support of our mission.

Joseph Aiken	Maggi Czoty	Brian Jenkins	Damian Neuberger	John I. Sullivan
Paul Albert	John Daffron	Michael Johnson	Marguerite Newhouse	Moutaz Sunbuli
Jeffrey Alvarado	Merilyn David	Joanne Justice	Pamela Niemann	Janice Sutton
Rudy Arce	Danielle Donegan	Patty Kelly	Michele O’Guinn	Diana Swartz
Rebecca Arrington	Kathleen Dowdle	Sharon Kelsay	Darcy Ode	Michelle Takemoto
Steven Asbury	John Durham	Roberta Kickbush	Erin Odell	Susan Tate
Tim Bailey	Joan Eaton	David Kiefer	Elizabeth Papin	Gail Thompson
Dolores Beattie	Philip Emerson	Daniel Kolopajlo	Bonnie Parsons	Pamela Thorkelson
Gary Bland	Debbie Endres	David Kramer	Matthew Pasick	Marty Thorpe
Robert Bock	Paul Enslin	Holly Kroeze	Lauren Patterson	Carol Timperly
Christopher Bonk	Eddie Escobar	Edward Kuhn	Lois Peddigree	Nicolas Torres
William Bostick	Margie Everett	Bruce Lambert	Ernest Pemberton	Chris Towe
Dawn Boyd	Amy Feriante	Jonathan Lausell	Toni Perez	John Tracy
Kevin Brady	Mary Jo Festle	James Layne	Eugene Prettyman	Larry Trout
Catherine Brosnan	Teresa Figueredo	Rachelle Ledbetter	Brian Puhalsky	Michael Tunn
Harold Brown	John Fox	Nancy Lee	David Reed	Lloyd Turner
Peter Brown	Doris Frick	Blaine Lesnik	Susan Reid	Carolyn Vega
Connie Buchs	Laura Garcia Aguinaga	Gail Lewis	Karen Reid	Dorothy Virgil
William Buckler	Loren Gebhardt	Jerome Lippert	Frances Reyes	Fred Walker
Cassie Buckner	Tamara Geunther	Maurice Lippert	Ralph Rhodes	Les Wall
Melissa Burke	Dan Griggs	Susan Long	Josephine Ricci	Dara Walker
Robin Burton	Timothy Groger	Laticia Long	Ellen Riley	Gregg Walters
Tim Calkins	Linda Grubb	Daryl Long	Gwenn Rosenberg	Kimberly Willhoite
Christine Capriati	Eric Harned	Ashraf Mahomed	Kay Ryan	Ina Williams
Pamela Carneal	Dave Harris	Jennifer McGrain	Marcy Ryan	Lance Wood
Mandy Carrasquillo	Mohammad Hayat	John McNamara	Chuck Schuele	Reana Woods
Teffy Chamoun	Thomas Hayes	Ed Merino	Margaret Seanor	Paul Woods
Marc Chelap	Mark Henry	Lorraine Merva	Gary Sherman	Richard Wyatt
Joyce Christian	Jack Hollenbach	Etta Milton	Kayla Shirell	Sharon Yaros
Dan Cihon	Douglas Hollifield	Carol Mitchell	Michael Sisk	Alisa Yocum
Tim Collins	Orlan Holmes	Marsha Moore	Sylvia Smith-Spyres	Anna Young
Thomas Cook	Kathryn Horn	Dylan Mortimer	Shawn Spence	Meghan Zagorski
Tom Corcoran	Ginger Hurt	Mary Narkevicius	Justin Stanley	
Doug Crawford	Denise Jacobs	Thomas E Nate	George E. Sterling Jr.	



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Second Wind Lung Transplant Association, Inc.
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Mentoring means I get to be there for others, at a crucial time when support is so important. It brings me joy to help others through my experiences as a lung recipient.

—TAMMY ROBINSON



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