



MAY 2020 – JULY 2020

Second Wind Responds to Economic Impact of Pandemic: Member Dues to Be Waived For One Year

The Second Wind Board of Directors, recognizing the economic hardships imposed by the COVID-19 pandemic, approved a measure whereby all members will be entitled to receive a temporary dues waiver for the period August 1, 2020 through July 31, 2021.

Lung transplant recipients and their families, as well as those on waiting lists, face many financial challenges related to the costs of the procedure, post-transplant medications, travel, etc., and the impact of the pandemic has made things much worse.

Many who have suffered job losses also lost access to their employer-provided health insurance as a result, making it difficult to keep up with the cost of their care.

While Second Wind annual dues are only \$25.00, the Board understands that even this small amount can be an obstacle for many, and we do not wish to lose members simply for lack of funds.

Here is how it will work:

• Beginning August 1st, those members whose membership expires during the period above will receive a notice that

it will be renewed automatically for one year, and that no payment will be required.

- Anyone who applies for a new membership during this same period will automatically be granted a dues waiver for their first year.
- As noted above, this waiver is to be temporary. Beginning as of September 1, 2021 we will again be charging annual dues of \$25.00.

The Board of Second Wind feels we have an obligation to do everything we can to help our members in the midst of this extraordinary health crisis.

Nonetheless, ours is a small, volunteer-staffed non-profit organization, and we too are encountering additional financial pressures. We will need to step up our fund-raising activities.

We encourage those of you who are financially able to do so to make a donation to Second Wind of any amount that you can afford.

Thanks for continuing to support us. Without our members there can be NO Second Wind.

Lung Transplants Used to Treat COVID-19

On June 5th a COVID-19 patient received a double-lung transplant at Northwestern Medicine in Chicago, the first such surgery in the U.S. done for this purpose since the pandemic began.

Doctors at Northwestern said the woman in her 20s had spent two months on devices to assist her heart and lungs in fighting the effects of the COVID-19 virus, and that it became clear that she would not have survived without a transplant.

"I certainly expect some of these patients will have such severe lung injury that they will not be able to carry on without transplant," said Ankit Bharat, Chief of Thoracic Surgery at Northwestern who performed the operation. "This could serve as a lifesaving intervention."

The patient's other organs have recovered, and her long-term prognosis is good, Bharat said, but she faces a long rehabilitation.

While this was the first COVID-19 related transplant in the U.S., it is believed that there have been a total of nine such operations worldwide, most of which have been performed in China.

The United States has suffered a shortage of transplant organs, with more than 100,000 people on waiting lists for kidneys, livers, lungs, hearts and other organs.

During the worst weeks of the pandemic the number of transplants dropped, but according to UNOS (United Network for Organ Sharing) the picture has improved. The number of transplants performed in 2020 was ahead of 2019's pace before the pandemic began, so the totals for the two years are comparable, their statistics show.

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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.

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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.



These have been interesting times since our last newsletter. There have been many challenges in our transplant community, but also some good changes. We have become closer as humans even if we are six feet apart and more sensitive to those that matter to us. There have been opportunities to be more generous with our time, our resources, and our kind words.

I know those who are waiting for new lungs were disheartened by the drop in the number of

transplants in the spring. However, those numbers have gradually increased, and by mid-July leveled off close to where they were before the pandemic. Let me share some other positive changes.

Transplant teams are working diligently to select donor lungs uninfected by COVID-19 to transplant to uninfected recipients, while maintaining safety for all involved. Several organizations collaborated to create a new protocol in this regard for use during the pandemic. Galvan, et al. (2020) reported on these guidelines in the American Journal of Transplantation.

The donor assessment includes two evaluations. First, the COVID-19 exposure history is assessed in depth. Then, the donor's clinical risk is measured using a detailed clinical history, the nasopharyngeal swab test, a chest CT scan to check for changes associated with the viral infection, and a bronchoscopy to collect a sample to test for COVID-19. Transplant candidates also undergo a nasopharyngeal swab and CT scan. Transplant teams follow an algorithm to guide their decision to transplant or to defer transplant. This protocol continues to evolve but the goal remains the same: 100% survival with no infection.

Zoom has become a household event in many homes as we meet for work or school demands. Teleconferencing has made it easier for health experts to talk to each other and keep current on the latest research. Telemedicine, which is becoming routine, allows for long distant screenings and treatment for patients and family members, which makes life easier for all involved. It is a practice that insurance companies will now reimburse for.

There has been a sense of urgency as the medical community and US Food and Drug Administration accelerate research into treatments for COVID-19 infections and vaccine production. This pandemic has created a system whereby scientists around the world are now comparing results as they measure the trends and the best interventions.

Many adults who survive COVID-19 will have residual lung damage and the need for a lung transplant. In mid-2020 three individuals from the US, Austria, and China hospitalized for

COVID required a lung transplant. Physicians are starting to report a "Post COVID Fibrosis Syndrome" where the resultant scarred lungs cause the individuals to experience pulmonary distress with severe shortness of breath.

The number of people who need Second Wind's services will grow in the next year, and you could be the agent that helps them find this needed support. You have read on page one about the Board's decision to waive all dues for one year in response to the pandemic's economic effects. We expect that more individuals can now join Second Wind and use all the resources we offer. This matches our mission and vision.

However, these services are not free. Our newsletter costs \$8,500 annually for printing and mailing. Our Email Support Group, Constant Contact services, HelpLine, Financial Assistance program, and web page hosting requires another \$20,000. We are confident that as you evaluate your values and priorities, those of you who can afford to support this organization will donate generously. And we hope that those who cannot afford to donate now will consider this later when things improve. We do not know how long this pandemic will last, but we need each other to survive and thrive.

UNOS (United Network for Organ Sharing) also seeks your help as a volunteer by sharing your time and expertise in one of their policy development roles. You as a transplant recipient or candidate can influence the donation and transplant community to save and enhance lives. If Interested, UNOS invites you to apply at https://optn.transplant.hrsa.gov/members/get-involved/.

If you prefer to direct your volunteer activities to Second Wind, we are searching for another director for the board and members for our Advisory Committee. The people who serve on that committee will be asked to donate their time on a specific project.

Examples of our needs include: a secretary to record minutes from the Board's six teleconference meetings per year, help with fundraising, and a website expert. If you have these or other skills not mentioned, contact me at Kurz@lasalle.edu. We are open to creative ideas!

Keep well and be safe!

Jane

RE-TRANSPLANT

Do I really want to do this again?

By Tom Nate, Board of Directors, Second Wind

"Tom, I'm so sorry. Your bronch results show you are in chronic rejection."

That is what my transplant coordinator told me in April 2008, exactly 11 months after my double lung transplant for Kartageners Syndrome and Bronchiectasis at Barnes-Jewish Hospital.

In February 2007 my wife and I and our five-year old son had relocated to St. Louis from San Antonio to wait for the call and on May 2nd it came. I received a pair of new lungs after a difficult 14-hour surgery. I almost didn't make it off the table due to heavy bleeding. I was heavily sedated for six days, but when I awoke I worked hard on my recovery and was released from the hospital in two weeks. Three months later we were home, and by September I was back to work.

I went back to St. Louis in March 2008 for a check up and the bronchoscopy showed no rejection, but soon after returning home my lung function numbers were dropping several points a day. Another trip to St. Louis, another bronch and in early April I learned I was in Chronic Rejection. By May my lung function was down to 40% of normal and dropping like a rock. My pulmonologist told me the only alternative was to try for retransplant.

Going home to tell my wife this news was harder than hearing it from the doctor, and much harder than telling her about the need for my first transplant. My wife was adamant—she didn't think

> again, and didn't want to go back to St. Louis because our son had just started first grade. I understood why she felt that way given what she'd gone through the first time, making life or death decisions for me while I was in surgery. She was even told at one point that I wasn't going to make it because they couldn't stop the bleeding inside

> > my chest cavity.

she could go through the process

I lay awake the next several nights trying to grasp whether I wanted to take this journey again. I had so many questions: Would they do a second surgery? Would it be as hard as the first one? Would I go through it only to confront rejection again soon after surgery? Most important, what impact would it have on my wife and young son to go through this all over again?

Ultimately my decision was easy. I <u>had</u> to try again. I couldn't fathom leaving my wife to raise my young son alone. I needed to be his father for as long as I could. So, after several long, deeply emotional conversations with my wife, we headed to St. Louis for evaluation for a second double-lung transplant.

"I <u>HAD</u> TO TRY AGAIN. I COULDN'T FATHOM LEAVING MY WIFE TO RAISE MY YOUNG SON ALONE."

I was told I qualified for re-transplant, but that because of all of the different antibodies I'd acquired from transfusions during my first surgery, I had less than a 2% chance of finding a matching donor. My doctor said I needed to decide soon if I wanted to continue because my lung function was declining fast. My wife and I left for home to decide whether to take this transplant journey one more time.

I was sure that I wanted to go through a second surgery, but had to convince my wife to go with me again. Being strong in our faith we decided to wait and pray for 40 days for a sign that I was supposed to go on this journey again. Within weeks we had offers of a private plane and a pilot, places in St. Louis to stay, and schools for my son. We knew these were signs that we were supposed to go forward, and in October 2008 we moved to St. Louis, enrolled my son in school and began the wait.

On New Years Day 2009 I awoke unable to get a full breath and took an ambulance to the hospital. After days of tests my doctor informed us that I had at best two weeks to live, and the chance of finding a donor in that time was almost nil. The feeling of numbness and total emptiness in the room after he left was excruciating for both of us. We did not speak. I remember sitting in the bed and staring at the wall. I was not ready to give up, but it was the most hopeless I had ever felt in my life.

That same night I went into cardiac arrest and suffered respiratory and kidney failure. The doctors called my wife at 1:00 a.m. and

told her to make plans for my demise, but she would not give in nor give up. She was my champion and insisted that the doctors do all they could to keep me alive. They did and I was kept sedated for weeks. When I awoke I was on a tracheostomy and swollen twice my size due to kidney failure.

After three months in Intensive Care I learned to walk and eat again. My kidneys started working and I was released with a portable vent connected to the trach that I could to use in our apartment. My wife found a scooter for me to ride and we rigged another vent on the back of the scooter so I could go anywhere, including to Barnes each day where I exercised. It's hard to believe now, but we lived this way for 18 months.

There were days when I would get depressed, but my son was

my built-in motivator. My depression was the result of not being able to help my wife raise my son, and knowing both of them were suffering watching me deteriorate. I never thought of giving up but after a conversation with a coordinator my wife and I wondered if we were wasting our time. I had been number one on the list for a year but still no donor had been found.

One month after that meeting I got The Call. It came at 1:00 a.m. and I woke my wife to discuss what we wanted to do. It was a difficult decision because the lungs came from a highrisk donor. After praying

about it together we agreed to accept the lungs. My wife noticed as we were getting ready to leave that my heart was pounding. I was bouncing between elation and anxiety, ready for what was coming, but remembering my first surgery and apprehensive about how it would go. After seven hours of surgery I awoke in ICU. This was the polar opposite of my first surgery—within

two days I was doing laps around the ICU pushing a wheelchair. I walked out of the hospital on October 10 2010 and have been blessed with very few health issues ever since.

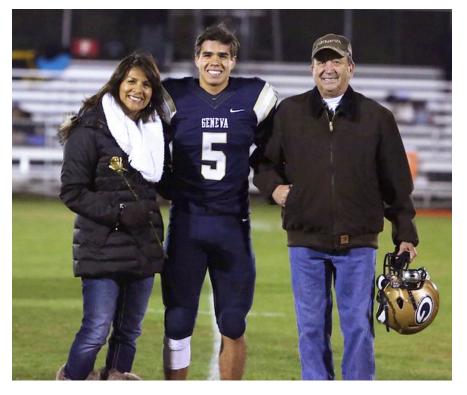
I've had an amazing quality of life the last 10 years, even attending my son's graduation from high school. I can honestly say that it was worth everything my family and I have been through. I'm 65 years old today but if chronic rejection surfaces again I would consider seeking a third transplant. My belief has always been to "never give up" and always fight to live. When God is ready for us, death will happen and we will have no say in the matter!

While successful, during the re-transplant process my wife and I experienced the full range of emotions; fear, anxiety, worry, hopelessness, frustration, anger, depression, guilt, joy, hope

elation, enthusiasm, satisfaction, regret and others I'm sure I've left out. We were much different people than when we started. It took counseling to realize that what we had been through was similar to what a soldier on the battlefield might experience. **PTSD** (Post traumatic stress disorder) is very real, the result of living each day not knowing whether it may be your last over an extended period of months.

My wife and I came to understand that we

would never be the same people we used to be. We learned to accept who we are today and to look forward to who we can be tomorrow. We are living life to the fullest, thanking God for His grace, and appreciating what it has taken us to get here.



Research & Technology: Improving the Odds for Lung Transplant Patients

By Emily Everett, Executive Director, Lung Transplant Foundation

The past few months have been especially challenging for lung transplant patients. With COVID-19 triggering an even greater threat to already fragile immune systems, many lung transplant patients found themselves more isolated than ever as out-patient clinics closed, and routine care came to a grinding halt.

Despite the setbacks from COVID-19, there are bright spots on the horizon for the lung transplant community thanks to the people who are working on innovative research and treatments to improve long-term outcomes for lung transplant patients.

A possible treatment for rejection is on the horizon. **Altavant Sciences** is one of a number of companies currently developing treatments for bronchiolitis obliterans syndrome (BOS), a lifethreatening complication of lung transplant in which the body rejects the new organ.

"While there are currently no effective treatments for BOS, there is strong scientific evidence that a drug like our candidate, ALTA-2530, may quell the innate immune response that drives BOS," says Altavant CEO Bill Symonds. "If this is proven successful in clinical trials, we would hope to see improved outcomes for transplant patients and improved outlooks for the thousands who count on the lifesaving promise of a lung transplant."

Currently conducting preclinical studies for ALTA-2530, Altavant expects to initiate a Phase 1 study in 2021. Following the completion of the Phase 1 study, they will then work with the lung transplant community to test the efficacy and safety of ALTA-2530 in patients with diagnosed BOS.

* * *

Although there have been temporary shutdowns due to COVID-19, researchers continue their work. The Clinical Trials in Organ Transplantation (CTOT) program is a network of investigators at five academic lung transplant centers led by Dr. Scott Palmer, Professor of Medicine and Vice Chair of Research for the Department of Medicine at Duke University Medical Center.

CTOT represents one of the largest efforts among leading lung transplant centers to work collaboratively, share data and patient samples and is focused directly on understanding the risk factors and mechanisms of Chronic Lung Allograft dysfunction (CLAD), a condition in which the body rejects the transplanted lungs.

"This sort of collaborative work is a major advance in the field, and we enrolled over 800 newly transplant patients in less than three years," says Dr. Palmer. "This level of patient engagement in research is wonderful credit to our patients and our lung transplant community who want to contribute

to helping others. Our ongoing studies and analysis of those patient's outcomes after transplant will shed new light on how lung infections and lung injury impact the risk for development of CLAD and will suggest new ways to prevent and treat CLAD."

Dr. Palmer notes that while research has experienced a temporary shut down due to COVID-19, doctors increasingly are finding ways to remotely consent and collect data from patients for studies to minimize risk to them but also allow us to continue to move forward research despite COVID-19.

* * *

Advances in medical technology are more critical than ever for lung transplant patients as new threats arise from COVID-19. Some companies are finding new uses for their products in development. Here are a few examples:

4DMedical has developed XV Technology Lung Ventilation Analysis Software (LVAS), a unique imaging process which produces valuable reports that illustrate lung health in an intuitive and engaging manner. LVAS is now FDA-cleared for use in the U.S.

Along with other clinical indicators, imaging where the lungs are receiving sufficient ventilation (air flowing in and out of the lungs) allows doctors and patients to decide on the best course of treatment. Functional imaging during regular breathing is much easier and more reproduceable than the measurements obtained from pulmonary function testing.

"The good news is all adult patients with lung disease, both acute and chronic can benefit for our XV Technology," says Andreas Fouras, CEO of 4DMedical. "This includes those with Asthma, COPD, Cystic Fibrosis, lung infections, Pulmonary Hypertension...(including)...patients considering lung transplant, or...(in)...post-transplant monitoring. We are confident that XV Technology will lead to better lung transplant patient outcomes."

Knowing COVID-19 involves a potential life-threatening virus affecting predominately the lungs, it is encouraging to know that XV Technology LVAS can potentially help patients in this pandemic. This includes providing better information on a patient's lung health status to healthcare professionals. This can help manage limited resources especially in the advent of spikes.

* * *

Lung transplantation technology and delivery systems have remained unchanged for 50 years. The current standard of care at transplant centers is packaging lungs in sterile bags on crushed ice without the ability to maintain the conditions of the organ.

There are not enough donor lungs for the patients who need them, and even when they do become available they can arrive injured, as the current ice cooler methods provide no temperature or pressure control. The team at **Paragonix** set out to design a more intuitive, safer product that would give the clinical teams, transplant recipients, and donor lungs every possible advantage to succeed and thrive.

"LUNGguard", a first-of-its-kind device developed by Paragonix is specifically engineered for lung transportation, while also designed to function with ease in stressful, high-stakes transplantation surgery environments. The LUNGguard System provides for quality management and control over the environment during transportation of lungs and is indicated for a storage time of up to eight hours.

In July, Paragonix received the international Red Dot design award for creating a novel solution to the challenging medical problem of organ transportation. Paragonix's LUNGguard has received FDA clearance in February 2020 and with the increasing demands of COVID on the lung transplant community the company is working to accelerate availability of this novel lung preservation device in the US and Europe.

"Lung donations are so critically needed and the decision for donation so significant, we set out to create a device that would provide the best technology to safeguard donor lungs", says Lisa Anderson, Paragonix President and COO. "With the onset of COVID it is more important than ever to ensure the best preservation and transport technology for the lung community."

* * *

The team at **patientMpower** has been working with people who have had lung transplants, and their clinical teams, for nearly three years. Their digital platform enables people who've had a lung transplant to monitor all of their vital signs at home, including lung function, temperature, oxygen saturation, and much more, and share this with their clinical teams back at their lung transplant center.

"Back then, we knew how valuable this was, to both patients and clinicians, in providing the reassurance of frequent (every day!) check-ups without the need for patients to travel to their transplant center," says Eamonn Costello, patientMpower CEO. "But we never could have envisaged a time then when patients couldn't attend a hospital for their routine check-ups. We feel so fortunate to have developed a technology back then that has proved to be so essential in the current crisis. We have been working hard to set up many new lung transplant centers with our home technology throughout COVID-19."

patientMpower has quadrupled the size of its team in the last few months to keep up with the demand for their home monitoring services. In addition to the demand for existing solutions, they were able to put expertise in this area to good use to quickly develop a solution for home monitoring of people with COVID-19. This approach was first used by hospitals across Ireland where it has helped manage their capacity and resources, and is now being used in the U.S. and the U.K. as well.

"Empowering patients to better manage their own conditions has always been the core of what we do," says Costello. "And COVID-19 has only reinforced this approach. More than ever it is so important for patients to be in control of their condition, with the support of the clinical team."

These are just a few of the major strides being made by cuttingedge companies on the forefront of emerging technologies to improve the quality of life for lung transplant patients. For more information, visit <u>lungtransplantfoundation.org</u>.

About the Lung Transplant Foundation

The mission of the Lung Transplant Foundation is to improve the lives of lung transplant patients and families. This is accomplished by promoting and advancing research to improve long-term outcomes among lung transplant recipients, educating and promoting awareness about organ donation, through patient support, education, and advocacy. For more information, visit lungtransplantfoundation.org.



What is a Caregiver?

Part 2 of the Ongoing Series, "Stayin' Alive"

By Tim Adams, Director, Second Wind Lung Transplant Association Lung Transplant Recipient – 19 June 2017



What truly is a caregiver? For the lung transplant patient, it surely is the most important question ever. Our caregivers might be the ones who do more to keep us alive than any doctor, nurse, or social worker. Let's think this through.

First, many of us never heard of a "caregiver" or barely understood its meaning. Maybe the first time we heard the phrase was when the Lung Transplant center asked who

would be your caregiver! If you didn't have an immediate answer to that question you were going to have a hard time with the hospital. They need to know because some of us believe we can take care of ourselves (we think of ourselves as an island) while the fact is, taking care of ourselves right after a lung transplant surgery is almost impossible. From day one we need help.

Remember trying to get out of bed in the hospital the first time to go to the bathroom? I was so frustrated. However, my lovely wife, Donnamarie, was there every moment to help do the simplest things. I couldn't eat, drink, or do almost anything in the new beginning without help. I surely didn't understand how this would change to other needs and on into the future.

I learned to do most things normally. I remember the first day I could walk, but the first time I took a shower, while overjoyed, I still needed help. Now, the nurses and rehab folks were there and unbelievably helpful, but my caregiver Donnamarie made everything possible. And now that we are almost three years into this new life, it's clearer than ever what a caregiver truly is.

My caregiver and I work together to protect me:

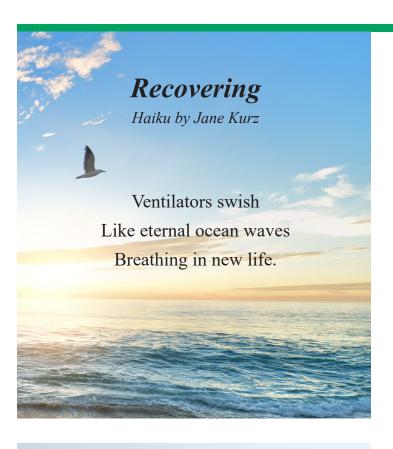
- 1. She protects the sanctity of our home. No one gets into our home without a "clearance" that includes questions about the health of the visitor. (Where can we get those magnetic identification cards?!)
- 2. I never leave home without personal protective equipment (PPE) including masks, gloves, and medications. Donnamarie wears all the same gear to protect herself from COVID-19 and to protect me. Wow!
- 3. She orders and maintains my medications. My job is to load up the weekly pill dispensers, understand the med schedule, take the meds at the proper times, and manage the insulin injections.

WHEN YOUR CAREGIVER SAYS, "WANT TO GO WALKING?" THE ONLY ANSWER IS "LOVE TO."

- 4. My caregiver helps with food choices and meals by counting carbs and calories and monitoring the temperatures of all the food we consume. I often hear, "Watch it, you're up to 35 carbs!" Whew!
- 5. Scheduling all my appointments with Temple University Hospital is carefully handled by my caretaker. Donnamarie has a great relationship with the LT center schedulers and never gets it wrong. Tight and careful scheduling is especially critical to us as we live so far from our hospital.
- 6. How is this for good teamwork? My caregiver and I discuss my blood tests and results. She is truly interested in the connections between the meds, their impact on the blood, and the differences in blood chemistry. This is important to us because I have had some wide variations in Vitamin D and Calcium levels in my blood.
- 7. Now if you, like me, are affected with some "minor mood changes" caused by the side effects of meds such as Prednisone, your caregiver will have some advice for you. Mine is from Philly and doesn't hesitate to say, "Cool it buddy or I'll knock you out!" This, of course, translates to "I love you. Relax, darling."
- 8. Finally, don't forget that whenever your caregiver asks, "Want to go walking?" the only answer is "Love to."

To close, I would like to remind all of you LT patients to remember that we also have a job—to take care of our caregivers as well as ourselves. Be sure to tell your caregiver that you are blessed to have them and how much you love them. Find ways every day to thank them for all they do.

And remember, "Stayin Alive" means doing all the things you need to do to stay healthy.



Coronavirus Weighing You Down?

The ongoing pandemic has caused us to spend more time at home and the lack of access to gyms, in-person exercise classes and other ways to stay in shape, can have a broadening affect on our waistlines.

A recent conversation on the Email Support Group centered on weight gains some have experienced as a result of self-quarantining. Two members identified technology that could help reduce the problem (pun intended).

Fred Harris and Carole Gibson-Morton recommended a free computer application known as "My Fitness Pal" which they use to track eating habits and control their weight.

The basic version has advertisements, but as Carole noted, "What advertising there is, is not a bit intrusive." Fred concurred, saying, "There's still plenty of good stuff in the basic app that you shouldn't need to upgrade."

Restaurant menu items and grocery store brands are listed on the website, so it's easy to click on what you ate and see the levels of protein, carbs and fats you've consumed. Fred added, "I liked that I could enter a recipe and get the nutritional information per serving."

My Fitness Pal is available online at Myfitnesspal.com, or as a download for your iPhone or Android device wherever apps are sold.



New Members

In addition to the names listed below, during the months of April through July 2020 we had four 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.

Joseph Aiken Joanne Justice William Bostick Sharon Kelsay John McNamara Kathleen Berg Tom Cook Dylan Mortimer Mary Lou Dykas **Buddy Norris** Jack Hollenbach Nicholas Torres Orlan Holmes Michael Tunn Brian Jenkins Carolyn Vega

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.

Carolyn Blalock	Fred Harris	
Gary Bland	Patrick Henry	
Lydia Burton	Cheryl Keeler	
Marc Chelap	Janice Laidlaw	
Jan Chicoine	Jim McClure	
Betsy Cichon	Tom Nate	
Kathy Cuenin	Michael Pazen	
John Curtin	Chuck Schuele	
Maggie Czoty	Frank Shields	
Diane Desiderio	Shiranne Simmons	
Doris Frick	Susan Sweeney	
Dan Griggs	Lance Wood	
Harlan Halvorson	David Yennior	

Financial Assistance Program Update

The Second Wind Financial Assistance Program (FAP) provides grants of up to \$500 to assist lung transplant patients and their families deal with the many unforeseen expenses related to the process. Since January 1st of this year FAP Committee volunteers have processed ten applications, and disbursed a total of \$4,200 to eligible individuals.

But numbers don't begin to tell the whole story. Time and time again we hear from patients and their caregivers how critical these small grants can be.

Here's one example, described by committee member and Second Wind Treasurer, Gary Bland:

"One of our FAP recipients, Frank S. passed away earlier this year. I got to know Frank and mostly his wife, Barbara (not their real names) as I handled their claim back in 2018. They were some of the nicest people I have ever met and were so grateful to Second Wind for helping them out financially. I knew from the way she talked in 2018 that Barbara did not have much money so she could not thank us enough. Speaking to her recently she said Frank would never have gotten his lung evaluation had we not helped them financially."

The FAP was established to help people like Frank and Barbara, and we know there are many more just like them who could use our help. Alas, our funds are running low and we could use some financial help ourselves.

If you'd like to learn more about the FAP, go to our website, 2ndwind.org and click on "Financial Aid". If you'd like to donate to this fund, click on the "Donate" button on the first page. Your donation will go help people experience the miracle that is lung transplantation.





Editor's Notes

- Don't miss the latest news in lung transplant research and technology on page six of this issue. Many thanks to Emily Everett of the Lung Transplant Foundation for sharing this valuable information with our readers.
- The friend who mentored me throughout my lung transplant journey once said, "Lung transplants aren't for sissies." and in this issue you'll read about a man who traveled this difficult path not once, but twice. Don't miss Tom Nate's remarkable story on page four.
- Everyone who has experienced a lung transplant will attest to the fact that that they couldn't have done it alone. Support from those closest to us is critical, and in part two of his "Stayin' Alive" series on page eight, Tim Adams explains how much the support of his caregiver, his wife Donnamarie, has meant to his survival.
- You'll notice that we did not include the listing of Support Groups in this issue. We recognize that some groups may be meeting virtually, but it's unlikely any groups are meeting in person. We hope that by the November issue this situation will have improved, and we'll include these listings again.
- You may also note the absence of any paid advertisements in this issue of *AirWays*. Ads are important because they help offset the cost of printing and mailing this newsletter and readers are interested in products that can help improve their lung health. If you or anyone you know is interested in hearing how a company can get its message in front of our thousands of readers, contact Frank Shields, Advertising Coordinator, by phone at (773) 925-9782 or via email at shieldsfr@aol.com.

- Patrick Henry Editor



Transplant Anniversaries

MAY 2020				
Name	Transplant Date	Years		
Rudy Arce	5/25/2019	1		
Marc Chelap	5/7/2013	7		
Maggi Czoty	5/2/2013	7		
Fred Harris	5/28/2016	4		
Timothy Monahan	5/14/2013	7		
Thomas Nate	5/3/2007	13		
Garry Nichols	5/9/2003	17		
Matthew Pasick	5/6/2019	1		
Lori Schilling	5/9/2003	17		
Justin Stanley	5/24/2019	1		
Robert Tharp	5/31/2016	4		
David Weist	5/28/2018	2		
David Yennior	5/2/2009	11		

JUNE 2020

Name	Transplant Date	Years
Teffy Chamoun	6/8/2019	1
Brian Conley	6/5/2015	5
Diane Desiderio	6/11/2001	19
Denise Jacobs	6/4/2017	3
Mary Narkevicius	6/10/2010	10
Helen Nichols	6/17/2019	1
Michael Olson	6/4/2014	6
Margaret Seanor	6/19/2018	2
Paul Woods	6/10/2013	7

JULY 2020

Name	Transplant Date	Years
John Curtin	7/20/2007	3
John Della Jacono	7/21/2019	1
John Douglas	7/20/2009	11
Steven Hargrave	7/9/2019	1
Daniel Kolopajlo	7/4/2019	1
Ruth Magnus	7/20/2008	12
Cathy McGill	7/13/1985	35
Michael Pazen	7/9/1999	21
Schuele Chuck	7/19/2010*	10
Frank Shields	7/16/2012	8
Anita Tracey	7/3/2005	15

^{*} ReTransplant Date

DONATIONS

General Fund

Betsy Cichon

Christine Coleman

John Curtin

Diane Disiderio

Doris Frick

Jim McClure

Michael Pazan

Chuck Schuele

Susan Sweeney

Financial Assistance Fund

Harlan Halvorson

Jim McClure

Chuck Schuele

Frank Shields

Financial Assistance Fund (In Honor of Frank Shields)

Bridgeport Rangers, SAC

Bernadette & Janet Buzelli

Mary Ann Kara

Judy Kettner

Kenneth & Linda Klode

Scott A. Lang

St Wendelin's Knights of Columbus

Thomas & Paula Staroba

Michael Sulla, Jr.

Salvatore Sulla

Deborah Zagorski

Matthew Zagorski

Mike Zagorski

Membership Assistance Fund

Jim McClure

In Memory of Sam Tambyraja

Shomala Tambyraja

In Honor of Bernice Funk

Cathy Cuenin

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



Please share this issue of AirWays with friends, family and colleagues.

Second Wind Lung Transplant Association, Inc. 75 Scattertree Lane Orchard Park, NY 14127

RETURN SERVICE REQUESTED



For those who have had or who are contemplating a lung transplant this can be a frightening time. Second Wind has "Peer Mentors", post lung transplant members who can be a source of information and advice. While Mentors never offer medical advice, they can share the benefit of their experience, or simply be there to listen.

Mentors will engage with you via phone and/or email, and stay connected with you throughout your lung transplant process if you wish.

To learn more go to 2ndwind.org and click on "Member Benefits", call our HELP line at 888-855-9463, or send an email to phenry2ndwind@gmail.com.