

A Word of Farewell & Thanks: Damian Neuberger, Ph.D.

Second Wind is sorry to announce that Damian Neuberger, one of the longest serving members of the Board of Directors, has tendered his resignation. After many years of service to Second Wind, he's decided that it is time to devote more of his energies to his health, and to the support of his wonderful wife, Judy.

Damian became a member of Second Wind in 1996, and joined the Board of Directors in 2005. Over the next 17 years he served in various roles, including Board Vice-President and, for a total of ten years, as Editor of *AirWays*. His devotion to Second Wind's mission, along with his scientific background, made Damian an exceedingly valuable resource to the Board.

Damian's transplant journey began in 1983 when he was diagnosed with Idiopathic Pulmonary Fibrosis (IPF). Although he never smoked, drank, or used drugs, the best reason for his diagnosis that the Mayo clinic could come up with was his exposure to chemical fixatives while working on his degrees. Genetics may also have played a part, as his paternal grandfather died in his 40s, and was described as having had weak lungs.

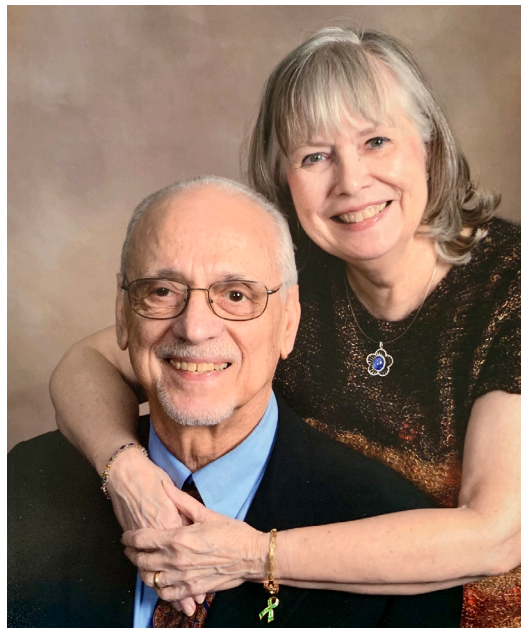
In 1983, the average life expectancy for people with IPF was only 3-5 years, and lung transplants were not yet an option. Damian did well until 1996, when he came down with a bad case of the flu. His pulmonologist put him on oxygen, and then, due to changes in his lung function, arranged for a lung transplant evaluation. He was listed on November 14, 1996 (his birthday) and, after an 11-month wait, was transplanted on October 19, 1997 at Loyola University Medical Center in Maywood, IL.

Damian recovered quickly and returned to work six weeks after transplant as a senior research scientist at Baxter Healthcare. Within eight months he was back to traveling for work and

vacations. Life had returned to normal with his family: wife, Judy, and their two adult children.

Damian understood well the wonderful gift of life he'd been given, noting:

"I am forever indebted to my donor, a 19-year-old young man, whose parents made this generous gift to me. I immediately wrote a thank you letter and during my six-week recovery I got a letter back from my donor's mom. We finally met in December 2000 and have continued to correspond and visit with each other. Over the years, we have attended weddings of my donor's cousins and they and others of the family attended my wife Judy and my 40th wedding anniversary celebration."



Fourteen years after his lung transplant, it became necessary for Damian to seek a kidney transplant. He was listed at the University of Wisconsin Hospital and, after a six and a half month wait, he received his kidney transplant on October 19, 2011.

Damian credits his good health to the care from two excellent transplant teams and "my following the rules while living my life." He also said that it is important to check the education, credentials and experience of physicians we select. His career taught him that, as in all scientific professions, medical professionals who train at more than one institution gain a more comprehensive view of their specialty.

The Board of Directors is unanimous in our respect and gratitude for the many contributions Damian Neuberger has made to the Second Wind Lung Transplant Association and its members over the past 17 years, and we wish him well in whatever the future may bring.

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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.

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. Original articles printed in *AirWays* become the property of 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

Tom Nate, President
Second Wind Lung Transplant Association, Inc.



As lung transplant patients, we are very accustomed to unexpected and sudden changes in our health (bumps in the road as we know them), and we then have to transition to whatever regimen our transplant centers and doctors recommend for us.

Transition has become a regular occurrence for our Second Wind Board of Directors lately, and not

in the way we would like. As most of you know, we lost two board members last year with the passing of Tim Adams and then Garry Nichols.

Tim's background in business and marketing made him a valuable board member. He, along with another board member, Frank Shields, worked long hours to create a very detailed strategic marketing and fundraising plan designed to improve Second Wind's profile in the non-profit community.

And Garry's loss was especially difficult because, as a very long-time member of the board, he was our "rock"—for his history and knowledge of our past business.

This past week we learned of another time of transition for our board with the resignation of long serving board member, Damian Neuberger. Like the late Garry Nichols, Damian has served in board positions since 2005, including two stints as our *AirWays* Newsletter editor. The cover story in this issue provides much more about Damian and his service to Second Wind, but I wanted to be the first to officially honor and offer my thanks to Damian for his contributions to our organization.

Thank you and well done, Sir! We will miss your knowledge, your insight and your lively banter during our board meetings, and wish you well in your retirement from the board.

Tom Nate,
President

thank
you



Editors' Notes

- Did you catch something different in the title up there? Yup, the term "Editor" is now plural! Second Wind is pleased to welcome Renae Woods, our new *AirWays* Co-Editor. You'll recognize Renae from her story in the November issue entitled "Criss-crossing America: A Transplant Journey." She's accepted the key task of generating and editing content for the bulk of this issue. Renae hasn't hesitated to jump into the breach, and her energy and commitment will result in a product that both informs and entertains our readers. Please join me in thanking Renae, and welcoming her to the *AirWays* family.
- As you'll see, much of this issue focuses on the COVID pandemic and its effects on lung transplant patients. There's important information here about how you and your family can stay safe as the Omicron variant continues to sweep the nation.

-Patrick Henry, Co-Editor

And now it's Renae's turn...

- I want to thank everyone for the warm welcome. I'm delighted to be Co-editor of *Airways*, Second Wind's quarterly newsletter! Special thanks to Patrick Henry. I'm motivated by his patience and knowledge.
- With every article, my goal is to spark your interest and light the path toward good health. And always, in everything, with every newsletter, we work together to exceed your expectations.
- If there is a specific topic you would like to know more about, don't hesitate to contact me at chooselife00@yahoo.com.

-Renae Woods, Co-Editor

Breaking News

The Food and Drug Administration has recently granted Emergency Authorization Approval for two new drugs to deal with the COVID-19 pandemic:

PAXLOVID:

The drug developed by Pfizer known as “Paxlovid” was authorized for patients age 12 and over who are vulnerable to becoming severely ill from COVID-19. This includes those who are elderly, have conditions such as obesity or diabetes, or are immunocompromised.

A clinical trial indicated that Paxlovid is effective when taken soon after people start feeling sick. In a study conducted while the Delta variant was surging, the drug reduced the risk of hospitalization or death by 88% when given to high-risk, unvaccinated adults within five days of the start of symptoms.

Until now, monoclonal antibody drugs, which are infused into the bloodstream, have been the only authorized treatments for Covid patients who are not hospitalized but at higher risk of developing severe disease. But these antibodies are available to fewer people than the pills are expected to reach, and there is no assurance that the antibody treatments will work against Omicron.

The federal government has ordered enough Paxlovid to cover 10 million people, at a cost of about \$530 per patient, but Pfizer initially provided only enough of the pills to cover 65,000 Americans. It is expected that they will make 200,000 treatment courses available in January, and another 150,000 in

February. Beginning in March the pace of deliveries is expected to increase sharply.

For more information, go to the website: pfizermedinfo.com and enter the search term, “paxlovid.”

EVUSHELD:

An Emergency Use Authorization was granted for the drug “Evusheld”, a pre-exposure prophylaxis of COVID-19 in adults, and children 12 years of age and older weighing at least 40 kg.

Evusheld is only indicated for individuals who have not had a known recent exposure to an individual infected with COVID. It is indicated for individuals who have moderate to severe immune compromise due to a medical condition, or receipt of immunosuppressive medications or treatments and may not mount an adequate immune response to COVID 19 vaccination. It is also indicated for individuals with a history of severe adverse reaction (e.g., severe allergic reaction) to COVID vaccines.

One dose of Evusheld is administered as two separate consecutive intramuscular injections (one injection per monoclonal antibody, given in immediate succession), and may be effective for pre-exposure prevention for up to six months. Evusheld is not authorized for individuals for the treatment of COVID-19 or for post-exposure prevention of COVID-19.

For more information, go to the website fda.gov and enter evusheld in the search area.

DONATIONS

Second Wind would like to thank the following individuals for their generous donation to help support our mission to serve the lung transplant population.

In Memoriam

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

Marion Peck

Transplanted 2011

Neal Singer

Transplanted 2019



General Fund

Mr & Mrs Andrew Laidlaw

Charles Schuele

Angela McCann-Lair

Michelle O'Guinn

Edward Kuhn

Michael Kilmer

Elena Khan

Financial Assistance Fund

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Catherine Cuenin

In Honor of

Dr. Andrew Courtwright

Shawn Acord

Mr & Mrs David Courtwright

In Honor of

**Patrick Henry -
Extraordinaire Retiring
Airways Editor**

Mr & Mrs. Hahn-Baker

In Honor of

**The Wedding of
Dr. & Mrs. Justin Rosenbeck
Their Guests at the Wedding**

In Honor of

Dick Wyatt

Mickey Lavender

In Honor of

Frank Shields

Patrick Henry

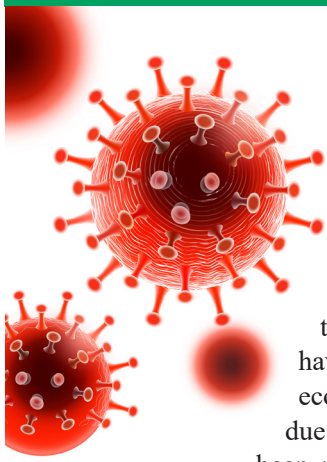
Sarah Ridder

In Memory of

Marion Peck

George Wilson

Nora Casey



Coronavirus Disease: 2019 – 2022

As we ring in 2022, we're also entering the third year of the COVID-19 pandemic. There have been devastating health and economic ramifications worldwide due to the disease. To date, there have been more than 290 million infections, resulting in almost 5.5 million deaths globally.

In the U.S. alone, there have been 848,885 deaths. But even more noteworthy are the number of people who have recovered from COVID: 41,722,468 patients contracted the disease and are now symptom-free and totally recovered. Long-term effects of COVID are unknown. Advances against COVID have come rapidly. Multiple effective vaccines emerged in the first year. The vaccine, including the booster shot, has cut the death rate by 90%. Hospitalizations are remarkably less as well.

Now we are preoccupied with mutations of Coronavirus. Delta and Omicron variants are highly transmissible and are sending people to the hospitals, stressing the health care system once again. Over 90% of those hospitalized with the Delta variant were not vaccinated. Health care officials stress over and over the importance of the vaccine.

The vaccine will save your life!

Scientists have reported that Omicron is so highly transmissible that eventually most everyone in the world will be infected. The Omicron variant has not been as serious causing severe illness and death in vaccinated individuals. What Omicron does is it cuts vaccine protection by more than 25-fold in people who have the 2 shot course of Moderna, Pfizer, or 1 shot of J&J. However, the booster brings the antibody levels back to where they were before Omicron. So the booster, or 3rd shot, is recommended as the best course of action to prevent the spread of COVID-19. Many transplant centers are recommending a 4th shot, or 2nd booster, for lung transplant patients 6 months after the 1st booster shot. Check with your coordinator or transplant pulmonologist for recommendations about the 4th shot.

Lung Transplants for COVID Patients

About 1 of 10 lung transplants in the U.S. now go to COVID-19 patients, according to United Network for Organ Sharing (UNOS). The vast majority of COVID patients receiving lung transplants chose not to be vaccinated against coronavirus. Approximately 250 people across the country have received lung transplants due to COVID. The first transplant was done in August of 2020. In Canada there is a huge surge of lung transplants due to COVID also. Dr. David Mulligan, the chair of the Yale-New Haven Health Transplant Center, says the COVID transplant surge is a big problem. Many critical COVID patients are receiving lung transplants causing other patients to wait longer. Doctors are forced to grapple with how to best manage who gets them, especially now that vaccines are widely available.

"When somebody contracts such severe COVID that they need a lung transplant, and they got it refusing to get a vaccine, it's really an ethical dilemma," says Mulligan. "How can they just jump in and take a lung away from somebody who's sick, but has been doing the best they can to take care of themselves and avoid getting COVID?"

Transplant centers take into consideration a lot of factors before listing someone as a good candidate for transplant. Past behaviors, and social factors, such as how people became sick, are usually overlooked as long as the patient is currently practicing a healthy lifestyle. Case in point: A person who smoked can be eligible for lung transplant, just like a person who drank alcohol in excess can be listed for a new liver, as long as they've stayed smoke-free and sober for 6 months. Not judging people's past

behavior is standard in medicine. But future behavior, when it comes to transplant, is fair game. A transplant is futile if unhealthy lifestyles persist. If the patient is not expected to live long enough for testing to be completed is the only pass for not meeting all requirements, such as vaccinations. Vaccinations would be administered after transplant in those cases.

Some say eliminating those who refuse COVID vaccine is unfair and a violation of civil rights. It excludes some religious and ethnic groups whose beliefs about vaccines are different. There is a caregiver dilemma as well. In many centers, it is recommended that caregivers of transplant patients be vaccinated against coronavirus. Transplant patients have a suppressed immune system, and they don't mount a normal immunologic response to the vaccine. Therefore, they don't have the same degree of protection as a normal individual would. So, it is recommended that everyone living with a transplant recipient be vaccinated against COVID-19.

Let's dialogue:

1. Do you think lung transplant recipients should be required to get COVID-19 vaccination including boosters prior to being listed?
2. Should caregivers be required to vaccinate?

Join me on the Email Support Group to dialogue. If you are not signed up and want to participate, contact Tom Nate: tnate1254@gmail.com. He will walk you through getting signed up.

I Managed to Hide from COVID For Nearly 2 Years

By Eric Harned,
Second Wind Board of Directors
Double-lung Transplant,
December 2014, OSU Wexner Center

I'm writing this article to give hope to those of you out there who are currently battling COVID and/or those of you still trying to avoid COVID amidst the daily challenges we each endure amidst our post-transplant walk.

My name is Eric Harned and I just celebrated my 7-year double lungaversary on December 22, 2021. To date I have been blessed with great health, no rejection challenges and have been told that I am the poster boy for successful lung transplantation.

When COVID was first identified and the symptoms and outcomes were first announced, I was instantly very fearful, just like most of you I am guessing. I instantly requested to work from home to avoid exposure—a hibernation effort that began March 2, 2020 and has lasted up to now if I am being honest. Not only did I quit working from my cubicle in an office, I also quit shopping at grocery stores and/or other retail stores, unless it was a quick in and out—fully masked and often with gloves—once again trying to avoid exposure to COVID which was running rampant. Keeping in mind that by then the fears of how quickly COVID could kill transplantees with suppressed immunities like ours was all the talk. I also began to watch the news more closely, waiting to hear word that an acceptable

vaccine would soon be available and knowing that us high risk folks would be high on the list to get the first vaccine.

At the suggestion of my docs—I was quick to get the first Pfizer vaccine shot on 2/23/21 at a well-orchestrated cattle call set up at OSU Schottenstein Center and I was blessed to experience no side effects whatsoever. I then was scheduled to get the second vaccine on 3/16/2021, once again with no side effects—lucky me. I then amidst my monthly blood draws arranged to have an antibody test a couple months later – only to learn that the prior vaccines I had received had really done nothing as there were no antibodies present. Fortunately, apart from continuing to umpire baseball through the summer—which was my only real exposure to other people, I managed to stay COVID-free and healthy amidst the many people across the country that were dying.

Fast forward 6 months later, I then got in line for the booster that was being offered which I got at my local Kroger Pharmacy and once again no real side effects apart from a slight pain in my arm. Through all this I maintained my distance from people, rarely going anywhere unless I was masked and again still working from home. Fortunately for me, I continued to dodge the COVID bullet and remained healthy and thanking God daily for my clean bill of COVID health, all the while now reffing basketball as my only source of interaction with people for the most part.

Then came the 2021 holidays and short-term exposure with immediate family. I likewise continued reffing as we were in the heart of the season, but unfortunately on Christmas Eve my first cold/flu like symptoms in 7 years since my transplant developed just two days after my 7-year lungaversary. Amidst my illness, I was blessed to be off from reffing for two weeks because the schools were on winter break, and I began to pop more Vitamin C on top of my daily regimen of anti-rejection meds and supplements that have kept me healthy the past 7 years. But each day I did not improve I got worried that





COVID may have gotten its claws in me and I began to really worry. I administered a self-test for COVID on Christmas day and it was negative—so I breathed a sigh of relief. But my symptoms continued to get a bit worse—running nose, frequent cough, headaches, body aches, fatigue—but I still had my sense of taste and no fever, but I chose to take a second COVID self-test. Unfortunately, it came back positive on New Year's Eve just before the ball dropped, putting a real damper on the start of 2022 and injecting major worry considering all the non-transplanted people that have died prior from COVID, and knowing I was even more vulnerable than the average Joe.

**“COVID IS A SCARY PROPOSITION, AND WE ALL
NEED TO TAKE IT SERIOUSLY AND DO ALL WE CAN
TO PREVENT EXPOSURE...AND MOST OF ALL,
TRUST YOUR DOCS AND GET THE VACCINE.”**

To say I was worried was an understatement as once the test showed positive, I immediately called my transplant support line at OSU to address my options. Once I shared the news—they agreed to try and get me scheduled for the antibody infusion ASAP. Two days later I was in the chair getting infused, praying that this would be the cure all—and that I would be doing better immediately. It has now been nearly a week since that infusion, and although I have not gotten any worse—I still have the same mild symptoms—but each day I seem to be getting slightly better—although I remain very tired and still cough at times.

What I am trying to say through all this is that COVID is a scary proposition, and we ALL need to take it seriously, do all we can to prevent exposure, be vigilant and most of all trust your docs and get the vaccine and of course get the infusion if it's available to you if you do test positive. It doesn't hurt to pray as well—something I have been doing daily for nearly the past two years amidst these crazy times. Frankly, I feel blessed that I am still here to write this “day in the life” article and I continue to say thanks daily to my donor Rita whose organ donation decision over seven years ago saved my life and helped erase my 10-year health decline amidst bronchiectasis/idiopathic pulmonary fibrosis prior to my transplant.

Simply stated I have tried to fight COVID the best I can so that I can continue to promote organ donation and be a positive light through my role on the Board of Directors here at Second Wind. May each of you that reads this article gain hope and confidence from the words that I have shared, not to mention a bit of insight that you are not alone in your walk.

– Eric Harned

Donor Family Contacts: The Wisdom of Letters and Meeting

By Jane Kurz, Ph.D., RN



There have been many on the Email Support Group recently asking, “Should I send a note to my donor family after my lung transplant?” In the early days of transplantation, transplant teams discouraged individuals from contacting donor families. However, over the last decade teams have revised their view and will work to facilitate contact. Let me explain the typical process.

After a family agrees to organ donation at the time of an individual’s death, select organs are retrieved in the operating room and transplanted. About 2 weeks after the donation, the transplant coordinator sends a “thank you” letter to the family with very brief facts about the recipient. Graf in her book, “The Gift of Life” included a sample letter with these details: “The gift of your mother’s right kidney was given to a 60 year old mother who lived in the metropolitan area. ... The gift of her left kidney was given to a 57 year old man with several children. His kidney failure was due to chronic high blood pressure. He no longer requires dialysis. Unfortunately, during our evaluation we found that your mother’s lungs, heart and pancreas were not suitable for transplantation, and therefore were not surgically recovered.....” Some centers will only tell the recipient basic information about their donor, e.g., age, gender, and cause of death. Each U.S. center establishes guidelines for recipient-donor communication. The majority of centers will maintain confidentiality to protect the donor family and recipient. In Europe many countries have laws that prohibit the release of any information about donors or recipients to the other party, although transplant coordinators give recipients the opportunity to write an anonymous “thank you” letter to the donor family (Galasinski & Sque, 2018).

Typically, the organ recipient prepares a brief note to the family thanking them for their gift and generosity, while acknowledging their loss. Most centers will provide guidelines for those who want to write a letter. The recipient gives the unsigned note to the center’s transplant coordinator and the coordinator delivers it to the donor family. Neither party knows the identity of the other. Many patients have stated that it was important that they had an opportunity to express their gratitude, and families have shared that these unsigned letters have provided them comfort.

Most researchers report that contact by letter is preferred by both recipients and donor families as a first step. When donor families write, they often share information about their loved one’s likes, dislikes, or physical characteristics, and they express hope that the recipient is feeling better (Finn, 2000).

Some recipients, however, want this degree of anonymity relaxed. Some have asked that their transplant coordinator arrange meetings, and to allow the patient to write donor families with their identities revealed. Typically, that does not occur until later in the recipient’s recovery process, and only if both families and recipients agree. Let’s examine what is known about the advantages and disadvantages of contact to both groups. Unfortunately, very few researchers have addressed this topic but allow me to share what is known. Azurit et al. (2013) surveyed 75 organ recipients and 60 donor family members about their contact. It ranged from low intensity (letters and telephone calls) to high intensity (face-to-face meetings). The two preferred times for making contact were within a month of the donation and more than a year after the transplant. In this study, like others, the donor family demonstrated a stronger desire to make contact and to sustain it over time. Dicks et al. (2018) completed a systematic review of studies and reported 91% of donor families wanted some information about the recipients, and 60% expressed interest in meeting the recipient.

There were many advantages to the donor family who made contact with the recipient. They reported:

- 1) a sense of satisfaction at learning the success of their donation,
- 2) feeling good about making personal contact with the other party,
- 3) feeling strengthened in the decision to donate, and
- 4) a sense that the late donor was living on in the recipient.

Advantages to the recipient who met their donor family included: the ability to say “thank you” and closing the circle linking death to a new life, satisfying their curiosity about the donor and the family who was willing to donate. In this study, the disadvantages to both recipients and families were:

- 1) a sense of loss and guilt,
- 2) a sense of creating an emotional burden on the other party, and
- 3) expectations of the contact were not met.

Some recipients felt pain at seeing their donor family grieving their loved one's death. Donor families reported a renewed sense of bereavement when they met. However, 79% of those who made the contact felt satisfied with the contact, and 89% listed benefits to the contact. The study participants reported that the contact had its costs but almost all wanted to continue the contact.

Donor families are a special group that undergo primary and secondary losses during the transplant experience that lead to grief reactions. Grieving is a very individualized and multi-dimensional process that reflects culture, belief systems, and previous experiences with loss. Donor families typically report comfort in knowing that their loved ones' death helped others live. The act of donating the organs helps families cope with the loss, and assists their living in a world without that person.

“MANY PATIENTS HAVE STATED THAT IT WAS IMPORTANT THAT THEY HAD AN OPPORTUNITY TO EXPRESS THEIR GRATITUDE, AND FAMILIES HAVE SHARED THAT THESE UNSIGNED LETTERS HAVE PROVIDED THEM COMFORT.”

When a family agrees to donate, they expect the donated organs to be used. Corr et al. (2011), members of the National Donor Family Council, presented examples from their practice that described the secondary losses for donor families. In their article they reported situations when the donor family received notification that all the organs could not be used, when their organ recipient died, or when they received a report that the transplanted organ was no longer functioning. Family members reported grief reactions similar to the grief they experienced when their loved one first died. When these families were asked what helped them during their secondary losses, they reported hearing about the loss from the transplant coordinator or family in a timely manner and attending the funeral of the recipient. They reported that it caused them more pain if cards and letters suddenly stopped, when previously they were sent at specific times (e.g., holidays). They were left to create their own conclusion. Donor families in this study stressed the importance of educating them about transplantation. They often do not understand that transplantation is a treatment, not a cure, which extends the life or improves the quality of life for the recipient. These researchers suggest that professionals can minimize secondary losses by educating donor families who want contact with recipients about the potential of recipients' complications, rejection rates, and the life expectancy of typical recipients. Transplant coordinators need to share information about the recipient's death in a thoughtful, caring manner. Lastly, it was suggested that they should offer formal supports, e.g., grief counseling. Families in this study stated they were not prepared for their grief reaction with the recipient's death.

It is clear from these few studies that the anonymous thank you letter from recipient to donor family is appreciated and causes few negative reactions. There are advantages and disadvantages to both groups when recipients and donor families communicate directly by telephone, letters, or face-to-face. The decision to meet is complicated and could be facilitated by transplant coordinators during arranged meetings at donor recognition events, or transplant center events. It is possible that donor families do not want further contact with the recipient after the initial letter. Recipients should recognize that every individual has a different way of coping with their grief. It also is possible that recipients do not want to meet the donor family because they feel they do not have the emotional strength to include them in their complicated life.

There are no wrong decisions with regard to contact. One Second Wind member shared that she writes yearly to her donor family and has never heard from them. She stated, “I’ve talked to a lot of donor families and they are glad to get the letters but they cannot handle the idea of meeting or corresponding with the recipients. And I think that’s perfectly normal.” One might also find that they write a first letter and do not get a response for several years. This might reflect the time when the donor family is adapting to their loss and grief. Another Second Wind member reported that he talked often to his donor family by telephone for several years, and eventually attended the wedding of his donor's sister with positive responses from all. These are all variations of “normal”.

The question remains, “What is best for transplant recipients and donor families, and how can transplant center health care professionals help the process?” Does age, gender, religion, or cause of donor death affect the intensity or anonymity of the contact? More research certainly is needed to find these answers. If you have the opportunity to participate in a study examining this, please consider it. We all can help find the answers.





You'll Live Longer

There's no secret that regular **exercise** can boost energy, improve sleep, lower blood pressure, promote weight loss, and improve muscle tone, strength, and endurance. And for lung transplant patients, exercise can be even more important in that it strengthens the heart and lungs, increasing lung capacity and endurance.

Exercise induces deep breathing and coughing which clears the lungs of inflammation, decreasing the risk of infection. Cardiovascular disease is reduced by 40% with regular aerobic exercise, such as walking or biking. Osteoporosis is minimized with regular exercise. Muscle resistant exercises decrease the progression of bone loss and osteoporosis. Regular exercise is considered activities 2 to 3 times per week. Aerobic exercises are activities that elevate the heart rate consistently for a period of time, such as walking and biking. Non-aerobic or muscle resistant exercises are activities such as weight lifting, or Pilates and floor exercises.

Sleep plays an important role in your entire body's functioning. Not getting enough sleep can lead to heart problems like high blood pressure or heart attacks. That's because lack of sleep can cause your body to release cortisol, a stress hormone that triggers your heart to work harder. Your heart needs enough sleep to function properly. According to a study from the AAA Foundation for Traffic Safety, you're twice as likely to get in a car accident when you're cruising on 6-7 hours of sleep, compared to if you get a full 7.5-8 hours. Sleep 5 hours or less and your chances of a crash quadruple, because your reaction time slows down when your brain isn't fully rested.

Sleep also improves memory. Your mind is still at work while you sleep. Your mind is actually processing and consolidating your memories from the day. If you don't get enough sleep those memories are misplaced, or confused. Your mind may create false memories when you are sleep deprived.

Getting enough sleep and exercise are goals we can all achieve to maintain good health, physically and mentally. There are many ways to achieve these goals. Gyms offer exercise groups for all ages and levels. A sunset walk after dinner, or an exercise DVD can be beneficial in adding years to your life.

FDA Approves New CMV Drug

The Food and Drug Administration (FDA) has granted approval to Takeda Pharmaceuticals Company Limited for Livtency, the first drug to treat post-transplant cytomegalovirus (CMV) disease that doesn't respond to the typical, available antiviral treatments.

CMV is a type of herpes virus that commonly causes infection in patients after a stem cell or organ transplant. CMV infection can lead to CMV disease and have a major negative impact on transplant recipients, including loss of the transplanted organ and death.

Livtency (maribavir) is designed for treating adults and pediatric patients (12 years of age and older and weighing at least 35 kilograms) with CMV infection. It works by preventing the activity of human cytomegalovirus enzyme pUL97, thus blocking virus replication.

"Transplant recipients are at a much greater risk for complications and death when faced with a cytomegalovirus infection," said John Farley, M.D., M.P.H., director of the Office of Infectious Diseases in the FDA's Center for Drug Evaluation and Research. "Cytomegalovirus infections that are resistant or do not respond to available drugs are of even greater concern. Today's approval helps meet a significant unmet medical need by providing a treatment option for this patient population."

The most common side effects of Livtency include taste disturbance, nausea, diarrhea, vomiting and fatigue. Livtency may reduce the antiviral activity of ganciclovir and valganciclovir, so co-administration with these drugs is not recommended. Also, virologic failure due to resistance can occur during and after treatment with Livtency, therefore it is recommended that CMV DNA levels be monitored, and Livtency resistance checked if the patient is not responding to treatment or relapses.



Membership Renewals

The following individuals renewed their membership in Second Wind during the period November 2021 – January 2022.

We thank you for your continued support of our mission.

Lotfi Ben Abdallah	Patrick Haggerty	Fran Peach
Glenda Billings	Holly Hahn-Baker	Joan Powell
Robert Bochniak	Kathryn Hahn	Doug Powers
Michael Bonnette	Courtney Harris	Robert Purvis
Bernadette Boyd	Leland Herring	Dale Rankin Mack
Aaron Brooks	Erin E. Holzhausen	Robert Redfield
Charon Brown	Linda Hunter	Victoria Reid
Chathia Brown	Deanna Isley	Linda Robicheaux
Jocelyn T. Byers	Kenneth Jackson	Kenneth Rose
Martine Cantler	Jacob Jergensen	Dennis Rourke
Gregory Carneal	Sharon S. Kelsay	Bette A Rovolis
Sonia Castell	Richard Knecht	Judy Rumler
Nikole Caudle	Frances Lambert	Jerry Russell
Donna Chadrick-Heath	Perseus Lark	Cheryl Salzar
Diane Chrones	LaDonne Lenzini	Larry Sanders
Veles Coe	Anne B. Lovett	Michael Savitt, M.D.
Julia Platt Cohn	David Lymangrover	Martha Skaggs
Annette Cook	James Lyons	Janet Slater
Taylin Cook	Gary Lytle	Irene Smiley
David W.Courtney	Douglas MacIntyre	Jeff Smos
Renee Crenshaw	Aldo Mancilla	Mark Steitz
Daniel Cupp	Julie Martin	Justin Stewart
Bruce Curry	Gabe Maznick	Greg Stone
Christina Cutsinger	Mickey McCabe	Marilyn Sundt
Timothy Davis	Kim McElhaney	John Swihart
Robert Dokes	Arapata Albert McKay	Phoebe Tarter
Michelle Dudenhefer	Nan McKenzie	Owen Teruel
Linda Easterly	Brad Messer	Shelly Toranto
Sam Elkurd	Altrisha Milton	Anita Tracey
Karen Ettinger	Timothy Monahan	Angela Wagner
Shantel Fierbaugh	Charles Moon	Johnny Watkins
Mark Full	Shirlee Newman	Michelle Wayteck
Melody Galchutt	Carla Noziska	Craig White
Maria Galsnapp	Michele O'Guinn	Paul Worthington
Mary Loretta Gallagher	Ruben Ogando	Dennis Wright
Christopher Gilmore	Blanca Iris Olivencia	Linda Yates
Theodore Gronska, M.D.	Brittany Patrick	Ronald C. Zimmer
Deborah Grosso	Sandra Patrick	Cynthia Zours

Transplant Anniversaries

NOVEMBER 2021

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
Fran Peach	11/23/2018	3

DECEMBER 2021

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
James Austin	12/18/2019	2
Robert Bochiak	12/17/2017	4
Gregory Carneal	12/11/2020	1
Betsy Cichon	12/16/2004	17
Doug Crawford	12/21/2019	2
Mark Falk	12/3/2020	1
Gage Georgeff	12/14/2009	12
Michael Harmon	12/13/2019	2
Eric Harned	12/22/2014	7
James Helms	12/15/2019	2
Karen Joy	12/18/2017	4
Joanne Justice	12/6/2007	14
Janice Laidlaw	12/19/2017	4
Etta Milton	12/1/2017	4
C. Lorenzo Pope	12/4/2017	4
Janice Sutton	12/14/2012	9
Dorothy Virgil	12/25/2019	2
Fred Walker	12/15/2006	15

JANUARY 2022

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
Leslie Casey	1/24/2016	5
Dan Griggs	1/11/2016	5
Holly Hahn-Baker	1/3/1998	23
Blaine Lesnik	1/8/2015	6
Paula Moscariello	1/1/1994	27
Brian Puhalsky	1/30/2017	4
Joanel Reed	1/19/2019	2
Jeanne Roberts	1/1/2017	4
Laura Roix	1/7/2017	4
Sheila Tate	1/27/2020	1

New Members

The following individuals became members of Second Wind during the period November 2021 – January 2022. We welcome and thank you for your support of our mission.

Kandi Bastianelli	Celia England	Leland Larson	Gail Size
Sonia Castell	Jessica Funicello	Paul Swanson	Elizabeth Warner
Jeanne Ehrenberg	Mary Jo Hamilton	Frank Visgatis	



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Orchard Park, NY 14127

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opportunity to live.”
— Jerry Gilliland



Tina & Jerry
Gilliland

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lungtransplantfoundation.org/mentorship/

Facebook Page: @LTFJosephCarter



Lung Transplant Foundation Joseph J. Carter[®]
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