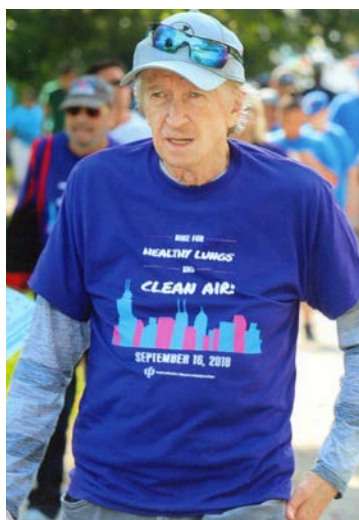


Frank Shields: February 18, 1947—February 4, 2022

Son, Brother, Uncle, Musician, Gardener, Fisherman, Super Salesman & Second Wind Force of Nature



*Frank leading his team at the
Hike for Lung Health*

Second Wind and the lung transplant community lost a tireless advocate when Frank Shields, our Board Vice-President, passed away this past February, just days shy of his 75th birthday.

It was in September 2010, after emergency gall bladder surgery, that Frank was diagnosed with Idiopathic Pulmonary Fibrosis and was placed on supplemental oxygen 24/7. In early 2012 he was listed and, after a five month wait, underwent a successful bilateral lung

transplant at the University of Chicago Medical Center. He joined the board of Second Wind two years later and continued to serve the organization as chief fundraiser right up until the day of his passing.

In addition to his work with Second Wind, Frank was a member of the University of Chicago Organ Transplant Support Group, the Easy Breathers Support Group at Christ Hospital Medical Center, Chicago Bridgeport VFW Post 5079, and the Knights of Columbus—Council # 12841. Lastly, he never missed a University of Chicago Transplant support group fundraiser or dinner, often accompanied by his niece, Meghan.

Frank's specialty was fundraising, and he worked tirelessly to support Second Wind and other non-profit organizations. He participated in the "Hustle Up the Hancock" where he successfully climbed 1,632 steps of the Hancock Tower with his nephew Michael Zagorski by his side. In addition, he led teams of walkers in the "Hike for Lung Health", an event sponsored by the Respiratory Health Association of Chicago, where he raised thousands of dollars to support Second Wind's Financial Assistance Program.

Frank was indeed, Second Wind's Super Salesman and, as the saying goes, "never stopped closing!". He couldn't let a board

meeting go by without sharing his latest ideas to increase the organization's revenue, and continually solicited donations from every commercial establishment with which he did business.

Frank graduated from Roosevelt University with dual Bachelor's degrees in Arts and Science, in the discipline of finance and was a Senior Business Analyst at Spiegel Inc. and its subsidiaries for 30 plus years. But his interests spanned far beyond the business world.

In his early years he played bass and formed a band with his brother and friends, The Malibu's. Soon the band was on to the road, playing in venues as far as Pittsburgh, Cleveland, and Louisville, Kentucky. Though his days with a band ended, his devotion toward music never waned. His nieces and nephews remember fondly that he would tend to his garden while his car radio loudly emitted the sounds of The Rascals, Chicago, Anita Baker, and the Bee Gees.

Tending that garden at his home in Lake Carroll was another of Frank's passions. He was famously known for growing the most wonderful assortment of blueberries, tomatoes and peppers. And he spent many memorable hours on the lake, imparting his knowledge of fishing and boating to his favorite niece and nephews, Meg, Mike and, especially Matt, who spent countless weekends alongside his uncle.

As his sister Debbie described it, "Every Fourth of July was the pinnacle of the summer with Frank on the dock fishing, his father and mother in the boat waving to all passersby, while the remainder of the family and friends shared in the many adventures afforded by the lake; truly such festive times were due solely to Frank's generosity."

Frank was the son of the late Irene C. & Frank Shields, brother of Michael Shields & Deborah Zagorski, and proud uncle of Michael & John Shields & Michael, Matthew, and Meghan Zagorski.

The Second Wind Board of Directors sends its deepest condolences to Michael, Debbie and all of Frank's extended family and friends, of which there are many.

We'll not see the likes of Frank Shields again for a long, long time.

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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.

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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.



Greetings!

First, I want to express my personal condolences to the extended family of our Board Vice-President, Frank Shields, who passed away unexpectedly on February 4th of this year. As you'll read in this issue's cover story, Frank was an extremely dedicated and valuable member of our

Board, and he will be sorely missed.

Also, just as *AirWays* went to print we learned of another great loss. Sadly, Cathy Cuenin, who has handled our HELP Line for the past few years, passed away on April 19th. You'll learn more about Cathy and her contributions to Second Wind in our next issue.

I also want to take this opportunity to officially welcome our newest Board Member, Renae Woods. Renae is a lung transplant recipient (her personal story was in the November 2021 issue of *AirWays*) and has been contributing to Second Wind by assisting the *AirWays* Newsletter editor by writing and editing articles. We are so happy to have her as an official member of our Board of Directors moving forward, and pleased that she will continue to work on our newsletter publication.

In other Board news, Mike Kilmer, the board member who has been our mainstay on Information Technology issues, and who designed the Second Wind flyer in this issue, left the board last month. We thank him for his service and wish him well.

As most of you know, April is official Organ Donation Month! I'm sure there are many of you who are active in your local areas assisting with registering organ donors and supporting organ donation drives and events. For all of us in the world of lung transplantation, there is not a day that goes by that we don't think of our donors, grateful for their gift of life that allows us to breath normally each day. For those of us who have had two double lung transplants or in some cases three, we are extremely humbled and thankful, and fully understand the extreme need and importance of organ donation. UNOS and other research organizations have established that the most difficult organ to get are the lungs for transplant surgery. The easiest are the kidneys.

As outlined in an article in this issue, as of April, 2019 there were over 124,000 people awaiting organ transplants (1500 awaiting lung transplants) in the US. 2000 of those are children and more than half are minorities. Every 10 minutes another transplant candidate is added to the list. In the U.S., 20 people a day pass away while on a list for an organ transplant—a total

of 7000+ in 2021. Amazingly, over 95% of Americans are in favor of organ donation but only 54% are actually registered as donors. As of 2021, there are 169 million registered donors in the US but sadly, only 3 in 1000 actually become eligible donors because the donor dies in a way that causes decreased organ donation. Thus, the need for more registered donors is great. There is good news to report though. In 2021, for the 11th year in a row, the number of transplant surgeries in the US increased over the previous year's total, with over 40,000 transplant surgeries completed.

If you have never been involved in an organ donation drive event, I highly encourage your finding one in your local area to take part in. It is rewarding, and a way for lung transplant recipients to pay it forward. Your efforts to register donors could possibly lead to sign up one who will save the lives of 8 people by providing an organ, healing tissue and/or bone transplants to someone on the list. There is so much more to do!

Wishing each of you success as you recruit new organ donors into the system!

Tom Nate

President, Second Wind Lung Transplant Association

Editors' Notes

- This issue of *AirWays* is focused on the important role that caregivers play in the lives of lung transplant recipients. Every transplant center requires their patients to develop a plan for the post-transplant recovery period, and the key to that plan is the role of a caregiver, who is expected to be available 24 hours a day for up to eight weeks. Here you'll read both how various transplant patients came up with creative ways to meet this important requirement, as well as what it's like to perform the caregiver role
- Our thanks to all who contributed their personal stories to this special issue. We hope you enjoy it as much as we have enjoyed putting it together. We really want caregivers to know how important their role is, and how much they are appreciated.
- We are always happy to receive feedback on what you read here in *AirWays*—what you liked, as well as what you think could have been done better. And your suggestions for future articles, whether of a personal nature or on the latest scientific breakthrough, are always welcomed. Simply drop a line to Renae (chooselife00@yahoo.com) or Patrick (phenry2ndwind@gmail.com) and include your contact information.

Renae Woods & Patrick Henry, Co-Editors

New Second Wind Flyer Available!

Below you see a reduced copy of a new Second Wind flyer developed by board member, Mike Kilmer.
Printed full size it is a standard 8.5" x 11".

Our hope is that folks will share it with their transplant centers and doctors' offices to help publicize our services. You can receive either a PDF version that you can print yourself, or a small supply of hard copies that you can reproduce by emailing Patrick Henry at phenry2ndwind@gmail.com.



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WIND**
LUNG TRANSPLANT ASSOCIATION, INC.

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SECOND WIND LUNG TRANSPLANT ASSOCIATION

Second Wind Lung Transplant Association, Inc. was formed on April 17, 1995, by a small group of people who wanted to provide information about lung transplantation to others.

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SECOND WIND IS DEDICATED TO IMPROVING THE QUALITY OF LIFE FOR LUNG TRANSPLANT CANDIDATES.
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- 3 EMAIL SUPPORT GROUP**
THE CAREGIVER FOR A LUNG TRANSPLANT CANDIDATE OR RECIPIENT.
- 4 AIRWAYS NEWSLETTER**
AIRWAYS IS PUBLISHED FOUR TIMES PER YEAR BY THE ASSOCIATION.

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Update: Paxlovid & Evusheld

By Patrick Henry

In the last issue of AirWays we alerted you to the FDA's emergency authorization approval of two new drugs: Paxlovid and Evusheld. I want to update you with information I learned about these medications.

PAXLOVID:

This drug was authorized for patients who are elderly, have conditions such as obesity or diabetes, or are immuno-compromised. It is designed to be taken at the first sign of an active COVID infection.

I was able to obtain a prescription for Paxlovid from my primary physician, but when I checked with my Transplant Coordinator at the Cleveland Clinic, I was advised that I should NOT take this medication because of the way it interacts with one of my immune suppression drugs: Tacrolimus (Prograf).

The Coordinator suggested a better choice would be another new anti-viral medication, Molnupiravir, which does not interfere with Tacrolimus. However, from what I could gather, this drug

is only 30% effective in reducing the impact of COVID, much less than Paxlovid. Still, it's better than nothing for we immune compromised folks.

EVUSHELD:

The news on Evusheld, a drug designed to prevent or mitigate the impact of COVID infections in the immune compromised population, is better. My Transplant Center is advising all its patients to receive this drug. It is administered in two injections, and in order to maintain its effectiveness, must be re-administered every six months. Supplies of Evusheld are limited, but growing, and I was able to obtain a dose at a hospital within 25 miles of my home.

I found this site by using a Federal government website which provides information on the nationwide availability of all three drugs mentioned in this article. You can find this information by going to healthdata.gov and entering the name of any one of these drugs in the search box.

Blood Type Can Be Changed To Increase Donor Lungs

As reported at Science.org, new research shows that the blood type of some donated lungs could be altered before transplant, which means there is a bigger pool of universal donor lungs and less time on the waiting list for those in need.

The process works via a pair of enzymes – specifically, FpGalNAc deacetylase and FpGalactosaminidase—that on combination remove the antigens that distinguish red blood cells, converting blood type A lungs into universal type O.

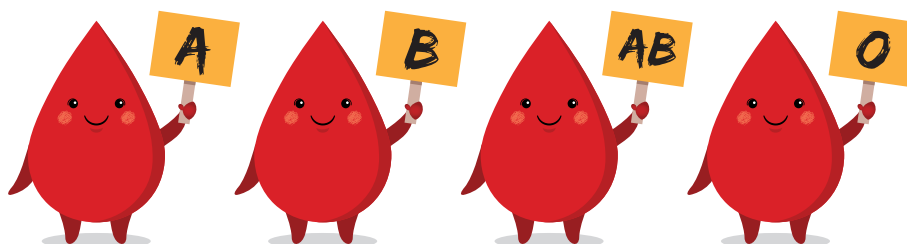
“There are about 100,000 patients on US organ transplant waiting lists,” the researchers write in their paper. “These patients require organs that must be compatible to their major cell surface antigens. The process to find compatible organs is not trivial.”

“Because of this, patients with progressively failing organs often wait years for a life-saving transplant, and some will die, never receiving an optimally matched organ. In 2017, less than one-third of patients on the lung transplant waiting list received an organ in the United States.”

The difficulty of finding matches means not just longer waiting times but also donated lungs going to waste.

Under lab conditions, scientists treated eight blood type A lungs with the enzyme combination, reporting that 97 percent of blood type A antigens were removed within four hours. What's more, the conversion was achieved without any observable toxicity.

To learn more about this breakthrough, go to Science.org and search under “blood type changes.”



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 Memory of Frank Shields

Bridge Port Rangers SAG

John Derby

Frances Hammon

Clarence Hasz

Christina McCutchan

St Wendelin's Knights of Columbus

Michael Shaughnessy

Susan Shinkus

Victoria Skaggs

Thomas Staroba

Quality Carpet Cleaning

Molly Everett

Alison Feldman

Daniel Griggs

Sheryl Helt

Knights of Columbus

Mary Anne Kara

Patrick Gibbons III

William Pranchke

Sue Skahill

In Memory of Tim Monahan

James Bucio

Catherine Byrne

Mark Gordon

Elise Wajid

Irene Castaldo

Melanie Trutt

Financial Assistance Program

Virginia Cuenin Trust

Donor Expresses Thanks For Second Wind

Recently we received a letter from Sheryl Helt, a member of Second Wind and the daughter of Kathryn Bryan, a double lung transplant recipient who was also a member. Sadly, the letter informed us that Kathryn passed away in June, 2020, four years after her transplant.

Sheryl sent us a donation in memory of her mother, and she shared kind words about what Second Wind meant to both of them. Here is an excerpt from her wonderful letter:

"We both joined the Second Wind Association and were grateful for the support and information your organization provides to both patients and their families. I know you are an all-volunteer organization, and I appreciate your service to all your fellow transplant recipients. It is an exclusive club that no one signs up for, but your uplifting messages and support really do make a difference. I wish you all the best and keep up the great work you're doing."

There are so many volunteers who have made Second Wind a successful source of support for transplant recipients over the past twenty-five years, and all deserve credit for their selfless contributions to our members. On their behalf, we thank Ms. Helt for her encouraging and heartfelt words of thanks.



My Caregiver

Please come and help me tie my shoe
I have come to depend so much on you
You assist me in all of my daily needs
I know I'm always calling your name it seems

You wipe away my tears and lift me up when I'm down
You are there for me when no one else is around
You are my strength that my body needs so
Your cheerful words always makes my heart glow

You are someone who stays with me when I'm ill
You listen and talk to me and seem to know exactly how I feel
You take away some of this stress with your friendly smiles
I know for me you would walk many many miles

You tell me not to be a quitter when I'm in pain
You say without me your life would not be the same
You give me your support and your loving care
I'm so thankful having a CAREGIVER like you my dear

Dedicated to all of the Care Givers
Glenda Jones

Caregiver Giving Her All

By Danielle Grosvenor

Almost 16 years ago, I Danielle, started a new role as transplant caregiver. My husband John received a double lung transplant on June 8, 2006 at Loyola Hospital in Maywood, Illinois.

As a caregiver my job was very important and very difficult. I had to keep track of all the appointments, tests, results, doctors, and medicines. Once John received the call for transplant, we headed to the hospital where my role became much more difficult. We lived 2 hours from the hospital so I had to stay there at the hospital in Maywood. We had a 5 year old at home, fortunately being cared for by grandparents making it possible for me to stay at the hospital.

The first week after transplant was very difficult. I got very little sleep and had to figure out what was needed once we got home. Needless to say, we didn't go home that week as planned. John had some breathing issues and had to be put back on the ventilator. At this point I was over tired and had a major meltdown! They took him to the ICU not knowing what was next. I slept in the waiting room for the next two weeks while John had his ups and downs. Every day, I checked his daily labs and talked with doctors and nurses. Then I relayed all this information to our families. After 2 weeks of being extremely sick, John was finally ready to come off the vent. He had to stay in ICU all the while I continued to sleep in the waiting room. Lots of preparation to come home started as I had to arrange therapy and medicine, not to mention getting our son ready to start kindergarten!

We arrived home with a huge mess of things that needed to be put away, and lots of appointments to be made, and medicine to be figured out! Being at home did not last very long. The next day when the home health nurse came, she shipped him right back to the hospital. So in again I loaded everything up and headed back to the hospital. Again, back at Loyola away from our son and support group, we had to spend another month. So in total we spent 3 months in the hospital.

Once finally home my work really began. I had to get everything organized, therapy appointments, doctor appointments, medications figured out and lined up, and I had to get our son to and from school daily.



Once we got into a routine it was much better but still a lot of work!! As the days and weeks passed, John had some ups and downs. He was in rejection twice, his gallbladder was removed, his hip was replaced, and he had to have the wires and bolts replaced in his chest because they broke!

Two years after transplant we had a miracle happen. We had our second son!!! Austin and Logan have had to go through a lot with their Dad being sick, but they have been a very big help.

In June it will be 16 years that John has had his new lungs, and he is doing very well. It is a wonderful thing that John got a second chance at life! Just remember behind every transplant recipient there is a caregiver giving their all to make sure things all go the right way!

Sincerely,

Danielle Grosvenor

What Is Family For?

A Caregiver's Story

By Hillary Loeb

We all have our own unique stories of how our loved ones became so sick that a transplant was necessary for survival. When, where, why, and how...is the disbelief that it is happening to "our" family. I remember when I thought this sort of thing only happens to other people, and was thankful that we "dodged that bullet." The reality is our health can change overnight, in a moment's notice. Some have slow, progressing warning signs and can be prepared for the inevitable, a transplant. For other people, like my husband Neal Singer, it happened so suddenly it created a total family crisis.

For several reasons my experience made such a huge impact on me that I feel the desire and need to share it with others. First is to set the facts straight with family, second to write this for our kids so things won't be forgotten, and thirdly, to connect with others who may have had a similar experience.

The title popped into my head one day while in the hospital room with Neal in the midst of all the chaos. I always thought that I had come from a close family and that they would be there for me in times of need. Surprisingly, I found out the hard way that my

belief was wrong. As it turned out, I was greatly disappointed by the family that I thought I could always count on.

This all started because Neal was born with the genetic predisposition for IPF (Interstitial Pulmonary Fibrosis). Sadly, his mother, brother, grandmother, aunt, and cousin all passed away from lung complications with unknown etiology, but an obvious genetic predisposition. Neal always suspected that he might develop the disease too one day since so many of his family members passed from it. His nightmare came true in the fall of 2019.

The old saying "timing is everything" did not hold true for Neal. It was bad timing, for Neal had just started a new job in real estate development out of state after a long drought of not working due to the economic recession. It was an exciting new opportunity in a new market and his career looked promising. Neal loved to work and we desperately needed the income. One of the things that I loved about him most was his passion for real estate and his drive to succeed. He was extremely intelligent too, for I often said that "he was a walking encyclopedia." Neal worked so hard to find this job, and to have him robbed by the failure of his own health, from which he had no control was definitely not his choosing. Yet Neal's extended family actually blamed and shamed Neal for getting so sick!

The chaos began with a strange call from Neal in mid -October. He had passed out and hit his head on concrete and was taken to the nearest community hospital, not the Cleveland Clinic in Weston FL where he was starting treatment before the transplant was recommended. I knew from that day forward our lives were going to drastically change and the excitement and contentment of a new job was going to come to a sudden halt.

I arrived to find Neal dazed and confused. Panicking but determined, I knew he was at the wrong hospital. He belonged at Cleveland Clinic where he recently began treatment. A total wreck, I called the Clinic for advice on how to get him transferred. I was told to demand an AMA form, which stands for "against medical advice." I did, and then couldn't get him dressed fast enough in dried bloody clothes as the nurse was pulling out his IV. Upon arriving at the Cleveland Clinic's emergency room, I could finally take a deep breath. I got him to the right place where they all knew him very well from past hospitalizations. "Hello, Mr. Singer...."

That moment of contentment was short lived because it became apparent that Neal's lungs were shutting down



completely, and he needed to get on the donor list asap. This was terrifying news. My stomach was in knots, I was totally numb and in complete and utter shock. How could this be happening now? But wait, Neal was finally happy with his new job and the big opportunity to finally get back on his feet after years of not working, and now to have his health fail on him? How much time left does he have? Will insurance cover this? What if he doesn't get a transplant in time? Will I lose my husband? Will my boys be fatherless? Logistically, how can I be in two places at the same time—home in Illinois with the boys or at the hospital with Neal? How on earth am I ever going to make this work?

**“MY LIFE WAS SPINNING OUT OF CONTROL LIKE A
TORNADO. EVERYTHING WAS BEING TURNED UPSIDE
DOWN. LIFE FELT SO HEAVY AND OVERWHELMING.”**

Obviously, the most important thing was to focus on getting Neal the best care possible. I remember a team doctor saying to Neal that he was to focus on nothing else but staying alive, eating, sleeping and walking. To keep his strength up as best as he could, and mental strength too, which meant letting go of work and family issues. Neal took that advice very seriously and was able to let go of minutia. Obviously, it was now my responsibility to take care of all the arrangements, which was a very hard task.

My life was spinning out of control like a tornado. Everything was being turned upside down. Life felt so heavy and overwhelming. How am I going to do it all? I need help, I am sinking, I can't breathe. I felt like I was crawling out of my skin, like I was on fire. I remember going to a private waiting room area and crying and telling my family and friends what was going on. I could see my reflection in the window looking out on to beautiful palm trees as tears drenched my shirt. I was so envious of the life outside the hospital and so badly wanted to be out there with Neal. Sometimes I would retreat to Neal's car in the parking lot where I would scream and cry, “I want my old life back, I want to go home, please help me God, I am begging you, please!” It was cathartic to cry and scream but it didn't change one single thing. My husband was dying and I had to find the courage and strength to pull everything together for all of us, I wanted my husband to live!

There were so many issues: logistically, emotionally, physically and financially. Logistically, the boys and I lived in Wilmette, Illinois and Neal was transferred to the Mayo Clinic in Jacksonville Florida. All three needed me, how can I be in two places at the same time? Impossible, so I had to find a live-in sitter to take care of our boys 24/7. My parents were too old now to take care of the boys, they mentally and physically

couldn't handle it. My mom who I used to be able to rely on was now easily frazzled and overwhelmed from taking care of my dad who was 10 years older than she was.

Another huge stressor was the relationship with my sister. She is six years older and has a tendency to be a bit bossy. She means well and has always been there for me when needed. She was the first person I called after I got that fateful phone call from Neal saying he was at “a hospital” after fainting. I was freaking out and couldn't even book my own flight to Florida. Within minutes she had me scheduled on the next flight to Ft. Lauderdale. I was and still am so thankful to have her as a sister. However, our relationship became strained by different perceptions, which led to miscommunication and misinterpretation. Some promises were made but difficult to make happen. I was incredibly grateful for her generous offer to pay for childcare, but she had her own ideas of what she would okay, which made it difficult to make a firm plan.

As we know, plans have to be fully established and approved by the transplant medical team. They need to know for certain that their patient will be well taken care of post-op. Unfortunately, my original sitter worked for a week and quit the day after New Year's. I hit rock bottom, worn out to the bone.

I remember the day when, sitting in my car I got a call from my sister refusing to pay a new sitter ready to start the very next day. That was followed by a call from the head nurse in charge of Neal's case, who was livid with me. They said that they, “Never would have agreed to Neal's transplant if they knew I would have such problems with child-care.” This was the most chilling and disturbing phone call I have ever received. Didn't everyone see how many hours and days I was putting into making something work? This left me feeling completely lost, alone and depleted.

Then Neal and I decided it'd be best to have a nurse be his caregiver post-op. We had it approved by the transplant team and it turned out to be the best decision. This way it'd be me instead of a stranger taking care of the kids. Plus, having professional care would leave the family drama out and allow Neal to concentrate on getting healthy.

In addition, Neal's side of the family was extremely disappointing. His older brother was the only living immediate relative left, and Neal needed his support. At first when I called to tell him what was going on, he didn't believe me, refusing to listen. But after visiting Neal he saw how sick he was, and then he became helpful. He was going to help with post-op care, for one week per month, but that plan didn't last because he became irate that Neal and I made the decision to hire a nurse instead of a distant cousin he'd recommended. Neal tried to make amends, but his

continued on page 10

brother ignored all of Neal's calls, texts and emails, and didn't even come to Neal's funeral 18 months later.

Looking back, it's hard not to feel so deeply hurt by my family. I thought they'd help more than they did. Through therapy I learned that all families have "layers," past events that build upon one another like bricks, and that shape us into who we are today. I can now better see those layers which help explain why I was so disappointed. I was deep in chaos, couldn't see straight and desperately needed help. But this was not about me but my husband, who was going through a true-life trauma. Neal was the one who faced death. Why couldn't relatives put aside their feelings and do more for their own blood relatives who were nothing but good to them? Wouldn't they want the same in return if they were in Neal's shoes? I totally believe you know who your true friends are in times of need like this. Funny, some of the people who I thought would help less, ended up helping more and vice versa.

Lastly, you may be wondering why I am using past tense regarding Neal. Sadly and unexpectedly, on 6-13-21 he was found deceased in a hotel room in North Carolina. It had been only two weeks after starting a new dream job. He developed pneumonia without knowing it, and it suddenly took his life. Such a tragic ending for a warrior. He fought so hard to live to have this happen. We didn't even get to say goodbye.

Strangely enough, my relationship with my mom and sister improved greatly because they were there for me when Neal passed. My sister flew in right away and helped me with all the arrangements for the funeral. When we visited Neal for the last time they escorted me to the funeral home. I thought I could do it on my own but they insisted, and I'm glad they did because it was the hardest thing I ever had to face in my life. They walked me into the room with their arms around my shoulders as my whole body trembled. I ran up to Neal and collapsed to the floor bawling, while my mom and sister rubbed my back and soothed me. They stayed with me, but gave me privacy and it was a good feeling that they were with me.

All in all, I wish that people could be more empathetic and understanding, and make more sacrifices to help their own family when in a crisis like mine. I was alone and in deep confusion and despair, for I desperately needed help from our family. Our own blood relatives, the ones we grew up with and shared a lifetime of special occasions and memories through the years. Birthdays, holidays, weddings—didn't that mean anything? I wasn't asking for permanent, long term help for it was a temporary, unplanned, but a true family crisis.

We are connected by parents and grandparents. We have built a family tree together, generations of people with the same genetics. Was I just dreaming that family would be there for us? Was it wishful thinking? A fantasy?

Medical Professionals & Caregiver Support



Dr. Zorba Paster, a renowned syndicated columnist and radio host, described a recent experience with a former patient who opened his eyes to how the medical professional community often overlooks the caregiver in their treatment plans.

This patient described how his wife was hospitalized for six weeks to undergo a stem cell transplant to treat her cancer, and while the doctors spent much time explaining to her what her recovery was going to be like he, the caregiver, was left out of the loop. Thus, he failed to understand just how difficult a time his wife went through, and was surprised by how she looked and responded when he first visited her. He asked why doctors don't do a better job of informing the patient's caregiver of what their loved one will be experiencing, so that they can be prepared to perform their important role during the recovery process.

Doctor Paster said, "We may talk and educate the patient, but how much do we educate the spouse, the partner, the relative or friend who cares for them?"

He noted that while there are support groups for many types of diseases, few focus on the problems faced by the caregivers, and went on to say, "We do a wonderful job when it comes to technology, to procedures, to surgeries, to advanced medical care. But when it comes to the human aspect of medicine, to the TLC and loving kindness, we still have a way to go."

It's important to remember that caregivers too have a role to play by taking responsibility to proactively seek out as much information as possible about their loved one's treatment if they feel that medical professionals are not holding up their end of the bargain.

Zorba Paster's radio programs can be found at
<https://www.wpr.org/programs/zorba-paster-your-health>



A Few Facts About Organ Donation

The Texas Organ Sharing Alliance recently sent us a list of basic facts about organ donations, and we want to share them with you. You can contact them at www.TOSA1.org for additional information.

- There is a severe shortage of organ donors in the U.S. Nearly 110,000 patients are currently on the national waiting list.
 - 2,000 are children
 - More than half are minorities
- A new name is added to the United Network for Organ Sharing waiting list every 10 minutes.
- More than 7,000 of the patients on the national waiting list died last year (*about 20 patients per day*) without ever receiving their transplant because there are not enough organs to transplant.
- Of the 2.3 million people who die in the U.S. every year, less than two percent are eligible to be organ donors. Almost everyone, however, can be a tissue donor.
- Transplant success rates increase when organs are matched between members of the same ethnic and racial group. A patient is less likely to reject a kidney if it is donated by an individual who is genetically similar. Therefore, a lack of organs donated by minorities can contribute to death and longer waiting periods for transplants for minorities.
- Donation does not disfigure the body or prevent an open casket funeral.
- Donated organs are removed in a sterile, surgical procedure, similar to open heart surgery, in a hospital operating room by skilled surgeons.
- Organ and tissue donation is considered only after all efforts to save the patient's life have been exhausted and death has been legally declared.
- There is no major religion in the U.S. that is opposed to organ and tissue donation. In fact, many religions endorse organ and tissue donation as an act of charity.
- Few people are too old or too young to donate. Currently there are no age limits for donors. At the time of your death, medical professionals will determine whether your organs are transplantable.
- Organs that can be transplanted are the heart, kidneys, pancreas, lungs, liver and intestine. One person can save eight lives!
- The organ allocation system is blind to wealth, celebrity and social status. Donated organs are placed in recipients based on best medical match and most critical need.
- No costs directly related to organ or tissue donation are passed on to the donor's family or estate.

Honoring A Life

We imagine that by now you have noticed how many of the donations listed in each issue of *AirWays* come to Second Wind as a way to recognize the loss of a close friend or family member.

These "In Memory of" donations are a wonderful way to both help Second Wind serve the transplant community, while honoring the memory of someone close to you who was either the recipient of a lung transplant, or acted as a caregiver for another who had been fortunate enough to have received this gift of life.

One way that individuals can generate donations in memory of a loved one is by listing Second Wind in the deceased's obituary as the recipient of donations to be given in that person's name. To do so, one need only refer such donations to be mailed to:

Second Wind Lung Transplant Assoc.
3590 Beckwith Lane
Crete, IL 60417

Anyone who sends a donation will receive a thank you letter from Second Wind and, upon their request, we will send a list of all donors to the deceased's family.

Sometimes It Takes An Army...

When you are going through the evaluation process to get listed for a lung transplant, there are a lot of tests, mostly physical that are done to insure that your body is physically capable to withstand the surgery and recover after. But for me, one of my biggest challenges was checking the box that I would have a



Before

dedicated caregiver to support me in my first 6 weeks post-transplant when I returned home.

My challenges were based on the fact that at 52, I was no longer married and not dating, so the idea of having a spouse care for me was out of the question. Likewise, my parents were too old and unable to drive to come care for me and my sister was working two

jobs so she was not able either. Lastly my kids were likewise unable, as my daughter was in boot camp with the Air Force and my son was away in college, hence I was facing a huge dilemma.

With this said, I discussed with the folks at OSU Wexner Medical if they would accept me for transplant if I could prove that there would be “a team of folks” committed to care for me and OSU said they would, but it would have to be substantiated, as self-care post-transplant was not an option.

From here I commenced to talk to my pastor, David Roberson at Worthington Christian Church and explain to him the dilemma I was facing. I told him I had less than 6 months to live and my only hope of an extended life would be through obtaining a lung transplant, but the challenge would be the post care for 6 weeks—24 hours a day to help insure my smooth recovery. Pastor Dave then took it to the congregation amidst all three services and they handed out commitment cards and over 150 people committed to help. From there two people, Terry and Martha took the lead in building a 6 week spreadsheet in Excel that allowed people to commit to 2 hour blocks and the 8 hour overnight shift, and within a week they had a fully committed schedule that Terry, Martha and several other church members and I took to OSU. We met with their team and explained the unique set-up for care that we had developed. They were

overwhelmed with what we had done, and although this was not the norm of having 1 or 2 dedicated caregivers for 6 weeks, they agreed to it and I was listed.

In looking back at this—and how over 100 people took an active hand in my post care over that 6-week window in early 2015 after my transplant—I know that God had a hand in all this and I remain a member of this church to this day. I likewise remain eternally grateful to all of them and my former Pastor who chose to take it to the church and make this unique ask of the whole congregation.

In hindsight, many of the people who participated have since told me personally that signing up to care for me, do laundry, get groceries, help bathe me, keep my medicines straight, pick up prescriptions and take me to Dr. visits and my rehab appointments took them out of their comfort zone, but they felt they grew as a person stepping up to help me. All in all, our church grew through their shared experience caring for me—and it truly gives credit to the phrase—Sometimes it takes an army—as my army was the 100+ fellow Worthington Christian Church members who became caregivers, and who assisted in my post-transplant care.

God bless those with a serving heart!

*Eric Harned - Double Lung Transplant
- OSU Wexner Medical - 12/22/14*



After



Caregivers Appreciation

By Renae Woods

Reading all the caregiver stories in this newsletter has stirred up a deep sense of appreciation in my heart. Without a doubt, caregiving is demanding and often stressful. However, it is often very rewarding as well. Our contribution to another's well-being has undeniable and long lasting positive effects.

My children's grandparents kept them often when I worked lots of odd hours. My Dad in particular, the latter part of his life, would tell stories over and over of all the things he did with and for my kids. He ended every story with: "And I'm glad I did it." We all feel a great sense of satisfaction knowing that we made a positive impression on someone else's life.

Although we sometimes hear of families being torn apart by caregiver struggles, most caregivers still come away from the experience with a new perspective on life. Things that are important before, such as career and education, become somewhat inconsequential during the process. Caregivers often put their lives on hold to be there for their loved ones.

The assurance of our loved one's well-being weighs heavily as the more important goal. Furthermore, all the caregiver duties, such as keeping appointments, keeping up with medication times and doses, as well as talking to healthcare and insurance professionals are cognitive skills that can help sharpen the caregiver's mind and improve memory.

Caregiving is far from easy. Pablo Casals understood the benefits when he said: "The capacity to care is the thing that gives life its deepest significance and meaning."

A person who cares for others promotes a healthy and purposeful life for themselves. I've had many to care for me, and I know I'm alive and well today because they cared. Saying thank you doesn't really do enough, but it's the least we can do.

THANK YOU!!!

Financial Assistance Program Update

The Second Wind Financial Assistance Program (FAP) provides financial assistance to people who have received, or are in the process of being evaluated for a lung transplant. The program is designed to help pay for the many medical and non-medical expenses incurred by patients that are not covered by insurance. These can include the costs of temporary lodging, travel and/or drugs.

The FAP has specific dollar limits and a formal application process that must be followed in order to determine a transplant patient's eligibility. You can learn more about these requirements by going to our website: www.2ndwind.org and clicking on "Financial Aid" at the bottom of the home page.

We strongly encourage both patients and Transplant Center staff to explore our website to find out if we can be of service to patients and their families as they go through their transplant journey.

In Memoriam

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

Michael Brunick

Transplanted 2015

Kathryn Bryan

Transplanted 2016

Monica Felicia Clanton

Pre-Transplant

Tim Manahan

Transplanted 2013

Neal Singer

Transplanted 2019



Support For Patients & Caregivers

As we are all aware, Support Groups provide connection, support, and information for individuals with shared experiences and complicated lives that the general public would not be able to relate to or understand fully. To connect with someone who has experienced the same issues, and who has suggestions of how to resolve the issues is very empowering for all involved. Second Wind Lung Transplant Association is a group providing this type support. There are other groups listed below that provide support in much the same way. As a transplant recipient or caregiver, or transplant professional, you may be interested in being a part of multiple support groups.

Transplant Café

Transplant Cafe is an online community and social network that facilitates support, connections, and a virtual global social resource to all members of the organ, tissue, cellular and limb transplant community. Transplant recipients or individuals waiting for a transplant, professionals who work in the field of transplantation (medical, business, or nonprofit), caretakers, or living donors and donor families are welcome at TC.

<https://helloworld.org/transplantcafe/>

Lung Transplant Foundation

The Lung Transplant Foundation (LTF) was founded as a non-profit organization by a group of lung transplant recipients from Durham and Chapel Hill, NC. Since 2009, it has raised funds and been an advocate for lung transplant research. They also provide education and emotional support for transplant recipients and their caregivers through their Mentorship Program.

<https://lungtransplantfoundation.org>

AARP: Home Alone Alliance

The Home Alone Alliance is a partnership of public, private, and nonprofit sector organizations coming together to create guidance for healthcare professionals who engage with family caregivers and tools for family caregivers providing complex care.

<https://www.aarp.org/ppi/initiatives/home-alone-alliance/>

New Study To Look At Impact Of CMV On Adults Post-Transplant

Adelphi Values, a health research organization that works with pharmaceutical companies to assess the impact of health conditions and their treatments on peoples' lives, is conducting a study exploring the burden of cytomegalovirus (CMV) and its treatment on transplant recipients.

CMV infection is common in post-transplant patients, and can lead to various medical problems such as increased graft failure and mortality. Sometimes CMV lasts for a long time even if being treated with medicine, or can come back after you and your doctors think it has gone away.

Adelphi Values is looking to speak with adults **18 years of age or older** who are recipients of a solid organ transplant, or an allogeneic hematopoietic stem cell transplant (HSCT), **within the past five years**, and who have experienced a CMV infection that lasted for over two weeks despite treatment, or a CMV infection that came back after having been treated successfully.

Participation in the study will consist of a brief interviewer-administered questionnaire and a one-on-one, 60-minute telephone interview to discuss your experience with CMV infection, its treatment, and its impact on your life. Participants will receive \$120 for completing the 60-minute interview.

During this study, **no medication will be given or tested**. Your inclusion in the interviews will not replace or affect any care or assistance you are currently receiving, or may receive in the future. Your name and contact information will not be shared with anyone and will remain confidential.

If you wish to participate, or have any questions, please contact Samantha Power at Adelphi Values via email (Samantha.Power@adelphivalues.com) or by calling 617-399-9660, and reference study number TK8701A.



Membership Renewals

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

Allen Albert	Eunice Gibson-Sutton	Erica Miller
Jeffrey Anderson	Kaitlin Gorman	Paula Moscariello
William Anthony	Holly Hahn-Baker	Helen Nichols
Susan Balcerzak	Harlan Halvorson	Buddy Norris
Kathy Berg	James Helms	Michael Pazen
Roseanne Best	Patrick Henry	Julianne Pease
Marla Brown	Gwen Herron	Brandon Pritchett
Marie Budev	Byron Horton	Sharron Pustejovsky
Johnny Carter	Richard Hull	Joanel Read
Leslie Casey	Beth Hunley	Jeanne Roberts
Jan Chicoine	Sonia Joseph	Laura Roix
Karen Cole	Karen Joy	Shiranne Simmons
Brian Conley	Cheryl Keeler	David Somerville
Roger Daley	Robert Kevin King	Susan Sweeney
Jennifer DuBois	Janice Laidlaw	Sheila Tate
Mary Lou Dykas	Veronica Lobo	Charles Vigil
Garry Ernst	Mike Malette	Karen Vollten
Mark Falk	Peg Matthews	Scott Willoughby
Fernando Fernandez	Bethany McBee	Ann Wysong
Kevin Gargan	Jim McClure	

New Members

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

Eperanza Dreshner	Francesca Magee	Dan Scribner
Vince Dreshner	Dwayne Morrissey	Greg Thompson
Michael Haney	Richard Norene	Sharon Woodard
Maria Jordon	Brandon Pritchett	
Patrick Libens	Lisa Santistevan	

Transplant Anniversaries

FEBRUARY

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
Paul Albert	2/10/1993	29
John Daffron	2/24/2021	1
Karen Ettinger	2/1/2012	10
Eunice Gibson-Sutton	2/7/2002	20
Cheryl Keeler	2/3/2005	17
Peg Matthews	2/16/2010	12
Jim McClure	2/24/2018	4
Lorraine Merva	2/23/2021	1
Erin Odell	2/11/1998	24
Susan Reid	2/20/2019	3
Raju Shah	2/22/2019	3

MARCH

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
Marcy Ryan	3/26/2021	1
Lisa Santistevan	3/10/2012	10
Dan Scibner	3/10/2021	1
Reana Woods	3/9/2010	12

APRIL

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
Aunjelique Anderson	4/6/2019	3
Gary Bland	4/7/2009	13
Greg Briggs	4/30/1997	25
Mike Bushnell	4/22/2021	1
Thomas Cook	4/11/2012	10
Mary Lou Dykas	4/7/2019	3
Teresa Figueredo	4/29/2016	6
Bobbie Hicks	4/23/2019	3
Rick Kamm	4/9/2008	14
Bruce Lambert	4/4/2021	1
Dylan Mortimer	4/13/2019	3
Jose Navarrete	4/25/2019	3
Ernest Pemberton	4/14/2016	6
Ellen Riley	4/10/2021	1
Shiranne Simmons	4/8/2017	5

Thank you for your support



*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

“

I have been blessed
with a renewed
opportunity to live.”
— Jerry Gilliland



Tina & Jerry
Gilliland

Request a mentor here:

lungtransplantfoundation.org/mentorship/

Facebook Page: @LTFJosephCarter



Lung Transplant Foundation Joseph J. Carter[®]
Mentorship Program