

COVID Death Toll: 750,000 & Counting

By: Patrick Henry

(Note: the opinions expressed herein are solely those of the author, and may not reflect those of the Board of Directors of Second Wind or its members.)

The death toll from COVID-19 has reached record heights, although the very latest numbers indicate it may be leveling off again, most likely due to increased vaccination rates. Yet we continue to struggle over questions surrounding vaccines and mask wearing, issues that have divided communities and even families. With respect to the vaccine, there are many reasons to take it, and one that might surprise you.

It isn't simply that the unvaccinated are more likely to infect others, which is true, it's because those who are infected provide the virus a perfect home in which to replicate. And, the more people who are infected with COVID, the more places the virus has to mutate, and the greater the chance it will result in a new, more hazardous variant. These new variants, like Delta, are especially dangerous to those who have received an organ transplant, or are immune suppressed for other reasons.

Vaccines have an amazing historical record of protecting humanity from deadly diseases. George Washington ordered his troops to be vaccinated against smallpox, a mandate that saved the Revolutionary Army and the nation it was fighting to create.

Anyone over the age of 65 should remember going to the school cafeteria to receive the vaccine against polio. It was a new vaccine then with little in the way of a track record, but our parents didn't hesitate to have us take it. It saved countless lives, and many children from a life on crutches or inside an iron lung.

The data is clear—it's the unvaccinated who are filling ICU beds, especially in states that resist mandating the use of masks or encouraging vaccinations, both of which would help halt the spread of a pandemic that has already killed more Americans than the infamous 1918 flu epidemic.

Still, some people have questions about vaccines and masking.

Are these vaccines safe?

The three current vaccines—Pfizer, Moderna and J&J—were tested among tens of thousands of volunteers and have been

given formal approval by the FDA. The incidence of serious side effects from the vaccine itself is extraordinarily small, especially in comparison to the deadly effects of becoming infected with the virus.

Wasn't the vaccine created by Bill Gates in order to insert a microchip that tracks our movements?

While it is true that Gates and other wealthy individuals (like Dolly Parton) contributed funds to help develop and/or distribute vaccines, they had no direct or indirect involvement in the design or development of the vaccines themselves.

And, let's be honest. If you were seriously worried about someone tracking your movements, the first thing you would do is throw away your cell phone. These handy little devices are recording your exact location 24/7 and sharing it with your service provider.

**“...UNVACCINATED ARE FILLING ICU BEDS
...IN STATES THAT RESIST MANDATING
...MASKS OR ENCOURAGING VACCINATION.”**

Isn't wearing a mask a waste of time?

It's been proven that the COVID virus is spread primarily through the air, when an infected person sneezes or coughs out droplets that contain the virus. Wearing a mask does two things: it limits the amount of virus that is expelled by the sick individual, and it provides protection to those around him, blocking the virus from entering their nose or mouth.

Think of it this way—if face masks did nothing to prevent the spread of germs and viruses, then why is it that surgeons always wear them? Would those who doubt their efficacy really feel comfortable looking up from the operating room table to see a circle of smiling, mask-less faces staring down at them?

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Why should I take a vaccine or wear a mask when I'm not worried about getting sick? Aren't these personal decisions?

Of course they are, as are many other decisions that, while personal in nature, have consequences for the rest of society. For example, even if you've tested positive for COVID, whether or not you go about your normal routine rather than quarantining at home is, strictly speaking, your personal decision. To mingle with the public knowing you might spread the virus to others is clearly wrong, but it's your decision to make. Unfortunately, if you haven't been vaccinated, then by mixing with others without knowing whether or not you're positive for COVID, you are doing the same thing.

And, yes, while it's true that a vaccinated person can have a breakthrough infection and spread the virus, the odds of their doing so is drastically reduced because of the vaccine's impact, which reduces the amount of virus present in their system.

So what? Why should I worry about what happens to other people?

That's a good question. One that only you and your conscience can answer.

Editor's Notes

You may notice that this issue of *AirWays*, my last as Editor, is a bit different. As opposed to many articles on the latest medical advances, you'll see mostly personal stories, with members revealing how lung disease and transplantation has impacted their lives, and the lives of their families.

In this issue you'll find:

- The story of a journey a strong woman took from one end of the country to another, determined to obtain the transplant she needed to beat the disease that was destroying her lungs.
- The tale of someone who traded a life of freedom and adventure in the Alaskan outback, for one filled with doctors, hospitals and debilitating treatments, all the while continuing to search for the joy in every new day.
- How one family dealt with the genetic impact of Pulmonary Fibrosis, showing great courage as each generation faced the threat of this disease, with all working to support one another.
- Finally, there is the account of a woman who, after being cared for by her husband during her long transplant journey, came to care for him as he faced his own, life-threatening condition.

We hope you find inspiration in these stories of hope and courage. - Patrick Henry, Editor

COVID 19 & Organ Transplants

The impact of the COVID pandemic on organ transplantation continues to generate news.

Here are some of the latest developments:

UNOS Policy re: testing organs for COVID

Effective May 27, 2021 UNOS (United Network for Organ Sharing) established a policy that requires organ procurement organizations to perform COVID-19 tests on all potential lung donors and have test results available prior to transplant of the lungs. This policy is designed to allow lung transplant programs to evaluate the risk of potential donor transmission of the virus to potential recipients.

Multiple cases reported in recent months demonstrated the potential for donor-derived COVID-19 transmission to lung recipients when respiratory samples were not tested and results confirmed prior to transplant.

UC Hospital Denies Transplant to Unvaccinated Patient

As reported in the Washington Post on 10/6/21, UCHealth, a Colorado-based transplant center, is denying organ transplants to patients not vaccinated against the coronavirus in "almost all situations," citing studies that show these patients are much more likely to die if they get covid-19.

UCHealth did not identify the patient, but said the woman would be "inactivated" on a kidney transplant waiting list, and was given 30 days to start coronavirus vaccination. If she refused to be vaccinated, she would be removed from the list.

UCHealth's rules for transplants, said spokesman, Dan Weaver, are similar to those in other transplant centers in the United States.

COVID Vaccine More Effective in Younger Transplant Patients

In a press release dated 9/30/21, Johns Hopkins Medicine researchers reported that children between the ages of 12 and 18 who received an organ transplant appeared to have a stronger immune response than adults did after receiving the standard two-dose vaccination regimen against the virus that causes COVID-19.

"We found that nearly three-fourths of the pediatric transplant recipients we studied had a positive and protective antibody response after receiving two doses of the Pfizer/BioNTech vaccine, in contrast with many adult recipients evaluated in previous Johns Hopkins Medicine studies who needed a third dose," said study senior author Douglas Mogul, M.D., Ph.D., M.P.H., associate professor of pediatrics at Johns Hopkins Children's Center and the Johns Hopkins University School of Medicine.

A previous Johns Hopkins study examined the immune response for adult transplant recipients after a third mRNA vaccine dose. The findings revealed that a third of those who had negative antibody levels, and all who had low positive levels before the booster shot, increased their immune response afterward.

Criss-Crossing America: A Transplant Journey

By: Reana Renae Woods

Single Lung Transplant 3/9/10

It was in the fall of 2001 when I moved to the West Coast, chasing a dream. It was my first big move out of my home state of Oklahoma, and I was excited and anxious all at the same time. I had a new job, new relationships, new church, new everything. I think the stress must have kicked my immune system into overdrive because I had symptoms of arthritis and repetitive strain injury before moving, but much worse afterwards.

And then came a cough that never went away.

I was told I had pulmonary fibrosis in both lungs, but no firm diagnosis could ever be determined. I started feeling short of breath the next spring and needed oxygen.

I had many of the features of scleroderma, and was treated as a scleroderma patient, although I did not test positive for scleroderma. I read everything I could find about scleroderma and pulmonary fibrosis.

One of the medical journals I found was particularly helpful. It was published in the 70's when patients waited longer for lung transplants than today. I read that I could be asked to do drastic things—like quit my job, or relocate. The article warned that many patients take too long making plans and run out of time. Over half of the patients at that time died while waiting for transplant. So, when I was told to quit my job and relocate, I did not hesitate.

“I’VE HAD TO BE FLEXIBLE THROUGHOUT THE ENTIRE TRANSPLANT PROCESS. MY CAREGIVERS HAD TO BE FLEXIBLE AS WELL.”

In 2004 I moved to the East Coast and was being treated at Duke Medical Center. My daughter lived in the area at that time. I know living near her is primarily what decreased the inflammation and helped to improve my overall health. She was a lot of support. Also, Duke had a very good Pulmonary Rehab Program. It too was very beneficial. I learned a lot more about taking care of myself from staff, as well as from other patients.

Gastric reflux is often a problem with scleroderma, and I was taught the importance of sleeping with my head elevated to decrease the incidence of reflux and aspiration. I also learned that heart failure is common after many years after transplant due to the time the heart has spent compensating for low oxygen levels by beating faster to deliver more oxygenated blood. I learned that when you sleep with your feet elevated it takes a lot of stress off your heart. I believe all of this knowledge has given me longevity of life.

I had to relocate a second time because the only two hospitals that would likely do my transplant were the Cleveland Clinic or the University of Pittsburgh. I’ve had to be flexible throughout the entire transplant process. My caregivers had to be flexible as well.

I chose Pittsburgh and they recommended I stay at Family House, where I would be around other transplant patients, and I’m so glad I did. There were support groups and lectures, and volunteers who provided programs, food and gifts. I’m still in touch with many of the families I met there. Having unique experiences and going through them together creates a bond like no other.

I waited four months for transplant, and it was a perfect match. On March 9, 2010 I received a very healthy lung. It was such a close match it could have come from my sister.

I’ve had brilliant doctors, nurses, therapists, social workers, and angel pilots who transported me back and forth to appointments free of charge. There are so many more to thank, especially my donor and my family.

I’m extremely grateful to God for this new abundant life! Every day is a gift that I would not have had if it weren’t for all those who worked with me. I know God orchestrated this entire process and led me to the right people, the right places, at the right time, to get the right lung. Saying thank you is not really enough to express the gratitude I feel, but it’s the least I can do.

THANK YOU for all who have contributed to my transplant journey! May God bless you!



Donating to Second Wind Through iGive

We know that many of you shop on-line, especially now that the COVID pandemic has made in-store shopping a risky affair, and we want to alert you to an opportunity to help Second Wind while you shop.

When you shop using a website known as iGive, a part of every purchase goes to Second Wind.

At iGive, over 2,300 stores will provide an average donation of 3% of your purchase price to Second Wind every time you buy. Joining is free, and iGive will send us a check every month.

Curious if your favorite store participates in the iGive program and how much they donate? Then enter igive.com/html/merchantlist2.cfm in your browser. There you will find merchants

such as Staples (2% donation), GAP (1.6%), Best Western Hotels (2%), Pet Supermarket (3.2%) and many more.

Since 1997 iGive has grown to 350,000 members, and contributed over \$8 million dollars to support different charitable causes.

You can shop using their iGive Button (a browser extension), via the iGive website, or by using the iGive mobile app.

To join iGive and start helping Second Wind, go to the website iGive.com/SWLungTransplantAssoc and complete the membership form. It's that easy!



iGive.com™

Have You had CMV Post-Transplant?

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

Adelphi Values, a health research organization, is seeking participants for a study it is conducting to ascertain the burden of (CMV) and its treatment on transplant recipients

Adelphi 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 more than two weeks despite treatment, or a CMV infection that came back after having been treated successfully.

Participation consists 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 receive \$120 for completing the 60-minute interview.

No medication will be given or tested during this study, and participation in the study will not replace or affect any care or assistance you are currently receiving, or may receive in the future. Participants' 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.



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

Patricia Wheeler, Pre-transplant Patient

Kale Willis, Transplanted 2019

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.

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In Memory of Paul Mazza

Shelby Miller

Welcome, Cathy Cuenin!

Cathy Cuenin is the newest member of the Second Wind Board of Directors. She is a retired nurse, therapist and acupressure practitioner, and a seventeen-year survivor of a double lung transplant. She has written about her transplant story in a book—The Way I Walk, From Tugboat to Transplant—upon which this article is based.



I'm training for a distance run. I'll join my son, who really does run, another family, and a few more people, to make up a team that will run through the night, handing off something to one another, from Skagway, Alaska to Whitehorse, Yukon Territory. And in the morning, we'll all party, pleased with ourselves no matter

our place in the race, and inspired by one another's energy and effort, not to mention the beauty we've been traveling through.

But my lung blows out. I go to the office where I worked as a hospice nurse until a few months ago. It's filled with other nurses who can listen to my lungs. They do and they tell me to get myself to the ER. While in the hospital with a collapsed lung, a friend calls to tell me about a woman who has a strange lung disease, suggesting maybe I have the same. I do not appreciate her call! But, in the end, she's right. I have Lymphangioleiomyomatosis (LAM). And my lung won't stay up. I'm flown out of Juneau and cared for in Seattle, which trips off a grueling multi months-long effort to get my collapsed lung to stay up.

Many kindnesses visit us during this grueling time. Funny, isn't it? The most horrible times are often simultaneously the most wonderful. Pain and breathlessness and grief on one hand. Huge kindness and generosity on the other. After some time, my husband, Loren, and I return home to Juneau to our dog and two cats, our son off at school in Fairbanks, and beautiful beaches to walk and scream along. And time. Time to recover and adjust to our new terminal illness, time to adjust to living with lungs that could pop at any time, and time to try to build back up some strength after lounging for some months in hospital beds.

I know I've partially adjusted to my new reality when a doctor asks me, "How do you handle the fear of a lung collapse at any time?" and I easily respond, "I put it in my back pocket. Don't take it out unless I need it."

A year has passed. I can finally handle returning to work but I can't hike back into the majestic backcountry of this rainforest like I used to. Or travel up the frozen rivers on my skis to the face of the glaciers. And, despite my reluctance to face my new disease and prognosis, Loren, who faces this with me, travels back to Ohio for the LAM Conference, returns and draws me the graph using my pulmonary function numbers, indicating my time of death. He begs me to consider a lung transplant, or at least to get listed. And so, about 3 years after the collapse that started all this, I begin the process.

All of this takes place when getting listed was different than it will be in the future. At that time, one got on a list and then waited as they climbed to the top. Thanks to Loren identifying my time of death without the transplant, I am on early.

I continue working as a nurse in Alaska. Eventually, it gets too difficult despite the great help I have at the elementary school where I am the nurse. Staff members grab a walkie-talkie and run to the site of an injured child as I give directions on another walkie-talkie, making my way to the scene just as fast as my lungs and tank will let me. The kids love my oxygen tank. Disabled kids seem particularly pleased to have an adult among their ranks.

Almost three years later, I am blessed with new lungs, facilitated by the excellent physicians, nurses, and staff at UC-San Francisco. I have moved to the bay area in California to be near family and the center, but initially I am very reluctant to say I am ready. After quite some time and concern from loved ones and others in my transplant support group, I finally say I am willing to accept a call. I am called in within hours of being put on active status. That same day! And no dry run.

I don't know my donor family, despite letters of gratitude I send. So, I adopt and am adopted by other families who have made the difficult decision to share their loved one's heart, lungs, and eyes, and never heard from the recipient. I honor their grief and celebrate their generosity. And I bless my donor family in the silence of my heart.

In the many years after transplant, I have the good fortune to visit family and friends, to watch my son marry, to meet and know my granddaughter. To run again, to hike again, even to return a few summers to Southeast Alaska, to the land and waterways I came to love over the 30 years that we lived and worked there. Some of that time we lived aboard our tugboat,

**“I DON’T KNOW MY DONOR FAMILY,
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SO I BLESS...(THEM)...IN THE SILENCE OF MY HEART.”**

towing and hauling freight, and many years I worked as a hospice nurse, work I cherished. And I spent as much time as possible in the wild and majestic back country.

In addition to all the joys that visit us post-transplant, there are a lot of bumps along the way. I’m crisscrossed with scars—or battle wounds—to prove it.

For most of the time we live in Washington State, a ferry ride from Seattle. I transfer my care to the University of Washington Medical Center when we move from California. I receive excellent care from them. They help me navigate what seems unsolvable or hopeless at times.

As this AirWays newsletter comes out we’ll (as my caregiver, it’s my husband’s transplant too) be celebrating the 17-year mark. I have been in chronic rejection for about 6 years, experiencing a very slow decline. My mobility, breath, and energy are limited these days but my goal now is just as it was before transplant when my breath was declining. It’s my intention to take notice of the new and smaller sphere which is my new life, to face the fears and then chase them off, to experience the loss and grief and move on to being curious about and relishing my new sphere of existence. Likely as not, if I can refrain from judging it as limited, it is whole and enough.

I’ve long appreciated the volunteers of Second Wind, those who keep track of finances, put out the newsletter, organize the Peer Mentor program, oversee the Email Support Group, manage the Financial Assistance Program, and provide needed support to the organization.

I’m honored to join them by answering the Help Line. Until now, I didn’t know I could be helpful with my limited availability and energy. And I do feel helpful. Many of the callers are happy

to have a human being answer the phone. I can often hear the anxiety in their voices and relief at finding a real person. I enjoy being able to have a good long conversation with someone who is frightened by their condition and the thought of transplant, or with someone who’s loved one has died. I’ve had people call the Help Line who are looking for someone who will contradict their physician, or to ask me if they should let a loved one go. For these, I can only listen and reflect, always referring them back to their providers. Many callers are looking for financial support to manage the staggering cost of the transplant process and medications. How incredible that we can be of assistance.

When I’m not chatting on the Help Line or back in the hospital for some reason, I share poetry writing with a group of friends, and watercolor paint over zoom with my mother, sisters, and granddaughter. I walk the dog using my mobility scooter, facilitate a local anti-racism task force, and celebrate and share blessings with a small community church. Not to mention cherishing life with Loren, cooking, reading, and camping.



Sibling Support & the Transplant Journey

By: Jane Kurz, Ph. D, RN

American families now have fewer children, divorce later in life, and spend more of their lives as widows and widowers. Instead of a tree thick with branches, family trees today look more like bean poles.

Family is essential to success in the transplant process. To qualify for a lung transplant most centers require one to have a support person. Typically, the spouse or partner fills that role, assisting with care before and after transplant. Studies show that having a caregiver is associated with surviving and a good quality of life (Ladin et al, 2019; Maldonado, 2019). However, both caregivers and patients need social support. Why are sisters and brothers so important in the transplant journey? A sibling could provide that!

Social Support is the assistance and protection given to others (Langford, 1997). Emotional Support includes the provision of caring, empathy, love, and trust. You do this when you say, “I want the best for you”. Informational Support is sharing information or advice at a time of stress. It assists a person to problem solve. Instrumental Support is the giving of goods, services, or tangible aid. It could be giving money, assisting with tasks, or providing physical care. Finally, Appraisal or Affirmational Support involves communication which is relevant to self-evaluation. You used it when you said, “You are so helpful”.

The sibling relationship can be a resource for Social Support, as that relationship typically is the longest one that individuals will share with another human. It is universal across all cultures, nations, and the lifespan.

A lifetime of shared experiences influences the type of relationship that you have with your siblings as an adult. In adulthood there are 5 types of sibling relationships (Langer & Love, 2019): 1) Intimate and extremely devoted; 2) Congenial, where they are close and caring friends; 3) Loyal, based on common family history and obligations; 4) Apathetic, where there is a lack of connectedness; and, 5) Hostile, where the siblings are resentful and angry.

The sibling system can be complex. Families have become complex as parents divorce, re-partner, and form new families. Half-siblings share a biological connection with one parent only and might not live together. Stepsiblings are not biologically related but are linked when partners bring children from prior relationships into a new household (Sanner & Jensen, 2021). Siblings who do live together develop a shared history with negotiated responsibilities, routines, values, and traditions. This will impact how they interact as adults.

Most adults rate their sibling relationships as positive, and maintain contact with each other. Studies show that those who

used telephone or texting to do so had closer relationships than those who used only email or Facebook to maintain contact. Sister-sister pairs had the closest relationships and provided more support than other gender pairs. (Gilligan et al, 2020). In general, adults who had children or spouses had lower levels of contact with their siblings than adults who were single or childless. Contact and support increased between siblings following a divorce or widowhood. In one study with older adults, sibling relationships were characterized by warmth and low levels of conflict and parental favoritism. (Stocker et al., 2020). All of these positive sibling relationships are associated with good physical and mental health.

Sibling relationships become increasingly valued as we age. However, for some those relationships are influenced by past rivalries and conflicts. Sibling conflict is associated with loneliness, depression and hostility (Stocker et al., 2020). Many surviving relatives find those unresolved conflicts cause pain later. A life-threatening illness can generate a desire to re-establish contact and heal old wounds. To mend relationships, experts suggest self-reflection to consider what contributed to the poor relationship, and strategies to re-establish good interactions (Yoshimura, 2021).

Often, focusing on respectful communication that is meant to build trust can make amends. It might start with a simple email or telephone call. If that is too much, consider a letter to acknowledge your sibling’s feelings, to apologize for harm caused by the estrangement, and to express a desire to reconnect. If starting to make this connection is too difficult, working with an empathetic therapist might be helpful.

It is unfortunate that there has been no research about sibling relationships during the transplant journey. Applying information from studies about siblings with chronic illnesses is not the best strategy. Increasing knowledge of this important family relationship is needed. If you have the chance to participate in someone’s study, do it. Social workers should consider the siblings ties when discussing supports. Counselors might want to explore how the sibling relationship influenced other family relationships and individual well-being.

Transplant candidates, recipients and caregivers should work to maintain a good relationship with their brothers and sisters—wherever they are!

References supplied upon request.



PF: One Family's Struggle

By: Sarah Ridder, Treasurer, Second Wind Board of Directors

Pulmonary Fibrosis (PF) has devastated our family in so many ways that it makes this hard to write.

On January 12, 1983, our father, Oliver L. Grosvenor, 57, passed away from Interstitial Pulmonary Fibrosis, leaving behind 13 children, nine still at home who ranged in age from 13 months to 15 years, and a young widow who was left to raise this large family by herself.

I had just turned 9 when my father passed, a typical young girl who loved to run carefree through our 100-acre farm. We grew up enjoying a life of leisurely summers on the river, rafting from one end to the other, fishing, and picking apples and mulberries from our trees. We played hide and go seek from the barn to the top of the second story of our farmhouse. We helped mom pick the garden when the vegetables were ripe, a salt shaker in hand to eat tomatoes straight from the vine.

During these idyllic times of childhood, however, Dad was in the Danville, Illinois Veterans Hospital, trying to get healthy enough to return home. Daddy was so ill from PF that he would be there for weeks or months at a time. The further along the disease progressed, the longer my mom was becoming this incredible SUPER WOMAN! She managed to take care of the farm, all of us kids, including keeping us out of trouble, all without us ever hearing her cry from sorrow or despair. She was made of steel, and remains the steel pillar today, holding us together through the struggles of myself and my siblings. Without her strength, unconditional love, and passion for being the greatest mom ever, none of her children would have been as successful and independent as they became.

Fast forward to January 3, 2003, almost 20 years to the day of our dad's passing; I had a terrible skiing accident that would again forever change our close-knit family. When I went to the ER, the doctor was more concerned about my lungs than the broken clavicle and concussion. In June 2003, after an open lung biopsy, it was confirmed that I did have Pulmonary Fibrosis, the Familial form. This began a long road of heartbreak and despair for our family, as diagnosis after diagnosis confirmed that I and my siblings were positive for PF, the disease that robbed us of our father.

On June 16, 2005, PF took our brother Ray at age 48. Next, was our brother Roy (age 62) on December 7, 2008, then sisters Carolyn (58) on August 25, 2009 and finally Sharon (64) on August 6, 2010.

As for me, on March 15, 2006, I was blessed with the ultimate gift of life, a double lung transplant that spared me death from Pulmonary Fibrosis. Then, happily, on June 8, 2006 our brother John (25) received his life saving double lung transplant too. Another miracle occurred when a member of the 3rd generation, our nephew Ray Jr., was successfully transplanted on September 12, 2018.

While many in our family did die from Familial Interstitial Pulmonary Fibrosis, because of incredibly loving donor families, our mother was spared the loss of two of her children and one grandchild. And we have thrived.

My husband, Kevin, and I had a 14-year-old son Dorian at the time of my transplant, and he is now 29.

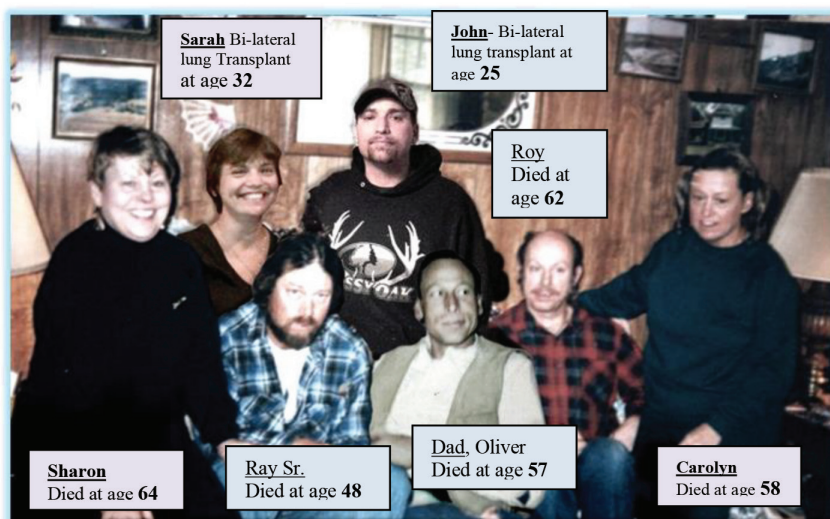
John and his wife, Danielle, had a son, Austin, who turned 5 while John was recovering from his transplant. Austin is

now 20 and serving our country in the U.S. Army! John and Danielle were blessed with another son, Logan, who is now 13.

Although I have been successful with my new lungs (with some setbacks along the way), the worst part of this disease is that my husband, Kevin, who has stood by my side for almost 20 years, never knows if he will have his wife around to grow old with. So we have crammed these past 15 years full of wonderful family memories, just in case.

We continue to worry incessantly about our siblings, their children and their grandchildren, petrified that we won't find a treatment or cure for PF. I am consumed with finding a cure, or at least a way to determine if the kids carry this disease inside their DNA, working with Vanderbilt University Hospital, Nashville, TN doing research.

I pray to God daily to help us get the funding and research so desperately needed to discover the gene or genes that cause PF.



Generous Strangers Create Miracles

By: Patrick Henry



I had lunch with a miracle the other day. Oh, she looked ordinary enough, and the other restaurant patrons may not have paid much attention to the attractive, energetic woman in animated conversation with me, but if they knew what I did, they might have stared in wonder.

The miracle, the wonder of her, if

you will, is the fact that she was there at all. It is a miracle born of modern medicine, of her determination and the support of family and friends, but most importantly, of a series of selfless decisions made by people she will never know.

Born with a condition that left her lungs defenseless against the mildest of environmental assaults, my friend Holly was in serious decline by her late thirties. Doctors had done their best to get her that far, and she had led a nearly normal life, but they couldn't stop the inevitable. Unless something changed, she was going to slowly suffocate to death. Then, because of the ultimate act of charity by a stranger, Holly received a double-lung transplant.

In addition to the skill of her medical team and that stranger's gift of life, Holly's continued presence in our lives is also the result of strict adherence to a lifelong regimen of powerful immunosuppression drugs and an obsessive vigilance against infections of any sort. Her dogged efforts in this regard demonstrate great respect for the gift she received.

Long term survival rates for double-lung transplant recipients are still uncertain—only 50% after five years—but Holly has beaten those odds. She is in year twenty-three, and making the most of her new, post-transplant life.

She volunteers for local non-profits, plays a pretty decent game of tennis (she and a partner medaled in Doubles at the U. S. Transplant Games) and is a dynamo in whatever she tackles.

As well as helping to improve her community, Holly provides critical emotional and physical support to her husband, David,

a man who was there to provide the same for her when she was facing her health crises. In one of those bittersweet ironies the universe seems so fond of, Dave's physical condition was becoming more serious just as Holly's was becoming less so, and this gave her the opportunity to return his loving favors.

And for me personally, someone who also suffered from a serious lung condition, Holly's example of how to cope with it while preparing for the possibility of something as risky and frightening as a major organ transplant was invaluable. She has been my role model and mentor.

As I sat there at lunch that day, I couldn't help but wonder what would have happened if the family of the person whose lungs now live inside her had not consented to the organ donation. In the midst of their own grief they were called upon to do for others, for people whom they did not know, and they came through. Reminiscent of *It's a Wonderful Life*, I thought about how Holly's post-transplant life has rippled out to touch so many of us, and was grateful again for their selfless act.

Unfortunately, and despite vigorous efforts to educate the public and the passage of laws designed to encourage them, organ donations have not kept up with the demand. 18 people die every day while waiting for a transplant.

If more people could experience what it's like to sit down to lunch with a miracle, I feel certain that would change.

(A version of this article appeared in the July 26, 2014 edition of The Buffalo News.)



New Members

The following individuals became members of Second Wind during the period August - October, 2021. We welcome and thank you for your support of our mission.

Christopher Bonk	Linda Grubb	Ellen Riley
Dawn Boyd	Dave Harris	Gary Sherman
Catherine Brosnan	Patty Kelly	Janice Sutton
Doug Crawford	Rachelle Ledbetter	Michelle Tackemoto
John Durham	Nancy Lee	Gail Thompson
Joan Eaton	Jerome Lippert	Fred Triquet
Phillip Emerson	Ed Merino	Ina Williams
Debbie Endres	Lorraine Merva	
Amy Feriante	Josephine Ricci	

Membership Renewals

The following individuals renewed their membership in Second Wind during the period August - October, 2021. We thank you for your continued support of our mission.

Jeffrey Alvarado	Edward Kuhn	Kay Ryan
Rudy Arce	Jonathan Lausell	Margaret Seanor
Robert Bock	James Layne	Michael Sisk
Kathryn Bryan	Maurice Lippert	Shawn Spence
Marie Budev	Daryl Long	Justin Stanley
Melissa Burke	Laticia Long	John I. Sullivan
Robin Burton	Ruth Magnus	Diana Swartz
Terri Christenson	Jennifer McGrain	Pamela Thorkelson
Joyce Christian	Etta Milton	Carol Timperly
Paul Enslin	Thomas E Nate	Lloyd Turner
Margie Everett	Mary Narkevicius	Chris Towe
Mary Jo Festle	Damian Neuberger	Dorothy Virgil
Teresa Figueredo	Pamela Niemann	Dara Walker
Tamara Geunther	Erin Odell	Fred Walker
Timothy Groger	Matthew Pasick	Les Wall
Eric Harned	Lois Peddigree	Paul Woods
Mark Henry	Ernest Pemberton	Reana Woods
Douglas Hollifield	Lisa Potter	Dave Worfel
Denise Jacobs	Brian Puhalsky	Sharon Yaros
Michael Johnson	Karen Reid	Meghan Zagorski
Daniel Kolopajlo	Frances Reyes	

Transplant Anniversaries

AUGUST 2021

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
William Bostick	8/15/2007	14
Jan Chicoine	8/16/2020	1
Tamara Geunther	8/15/2020	1
Harlan Halvorson	8/24/2006	15
Dave Harris	8/12/2016	5
Patrick Henry	8/25/2015	6
Gwen Herron	8/11/2012	9
Jack Hollenback	8/3/2007	14
Orlan Holmes	8/2/2002	19
Aldo Mancilla	8/13/2010	11
Julie Martin	8/29/2005	16
Ruben Ogando	8/18/2018	3
Michele O'Guinn	8/26/2004	17
Chris Towe	8/26/2018	3

SEPTEMBER 2021

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
Tim Calkins	9/29/2018	3
Paul Enslin	9/21/2019	2
Kevin Gargan	9/5/2016	5
Karina Hallinan	9/13/2019	2
Brian Jenkins	9/2/2009	12
Nancy Lee	9/23/2011	10
Veronica Lobo	9/5/2020	1
Daryl Long	9/4/2019	2
Michael Long	9/26/2019	2
Arapata Albert McKay	9/29/2020	1
John McNamara	9/18/2006	15
Cheree Peirce	9/16/2012	9
Pamela Thorkelson	9/17/2019	2
Lloyd Turner	9/27/2020	1
Carolyn Vega	9/1/2013	8

OCTOBER 2021

<u>Name</u>	<u>Transplant Date</u>	<u>Years</u>
Lotfi Ben Adballah	10/28/2020	1
John Berti	10/8/2019	2
Beth Davenport	10/20/1995	26
Julia Flatt Cohn	10/5/2020	1
Courtney Harris	10/16/2020	1
Sonia Joseph	10/23/2019	2
David Lischer	10/15/2017	4
Mickey McCabe	10/17/2016	5
Damian Neuberger	10/19/1997	24
Kay Ryan	10/18/2020	1
Alan Schwenck	10/6/2009	12
David Somerville	10/30/2017	4
Fred Triquet	10/21/2020	1
Charles Vigil	10/28/2018	3
Danette Ward	10/24/2019	2
Jennifer Wilcock	10/6/2019	2
Scott Willoughby	10/26/2017	4



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opportunity to live.”
— Jerry Gilliland**



Tina & Jerry
Gilliland

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lungtransplantfoundation.org/mentorship/

Facebook Page: @LTFJosephCarter



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Mentorship Program