“Continuous Distribution”
The Composite Allocation Score and The Changing Face of Lung Allocation
By Tonya Yurjevic, BSN, RN & Brian Keller, MD, PhD

So, you have been approved for a lung transplant and placed on the waiting list. Now what happens? How are lungs from a donor matched with you so you can receive a lifesaving lung transplant? Well, as of early March 2023, that process changed in the U.S. for the first time in 18 years. The new model, “Continuous Distribution”, seeks to enhance equity in lung allocation by improving access to transplants for historically hard to match candidates.

To understand Continuous Distribution, we must first look at from where we came. Prior to 2005, lungs were allocated on a first come, first-serve basis. The longer a candidate waited on the wait list, the higher their priority.

Unlike kidney or heart transplant candidates who have dialysis or mechanical circulatory support devices to maintain them while they wait for transplant, lung candidates have no such safety net. Therefore, the sickest patients were at high risk of dying without a transplant under this initial lung allocation model.

In 2005, the United Network for Organ Sharing (UNOS) developed a new model for lung allocation. This was called the Lung Allocation Score (LAS). The goal of this score was to prioritize the sickest patients and reduce death in people on the wait list. The score ranged from 0-100 and was calculated from formulas that considered a person’s estimated survival without a transplant, as well as the projected one-year post transplant survival.

Geographical distance was also considered in the allocation of lungs under this system, which meant that donor lungs would be offered first to potential recipients in a 250-mile radius from the donor hospital, and if the lungs were not allocated in that area, the geographical area was then widened. Despite reductions in wait list deaths and increased lung transplant rates, certain groups of patients were still at a disadvantage for receiving a transplant under this method.

On March 9, 2023, a new system was implemented for lung allocation called Continuous Distribution, which uses a new scoring metric, the Composite Allocation Score (CAS). The CAS removes the geographical boundaries that previously existed under the LAS, assigns all ages a score, and provides points to patients that may have a more difficult time matching with donors due to their height, blood type, or immune sensitization. The goal of the CAS is to prioritize the sickest patients, improve long-term survival, increase transplant opportunities for patients who are harder to match, and promote the efficiency of organ placement. (Pediatric donors still receive priority as explained below.)

“The GOAL OF THE CAS IS TO PRIORITIZE THE SICKEST PATIENTS...AND PROMOTE THE EFFICIENCY OF ORGAN PLACEMENT.”

The CAS, like the LAS, is a score ranging from 0-100. Under the CAS, up to 25 points are given based on medical urgency and up to 25 points are given based on projected survival five years after transplant.

The tests used for the calculation of medical urgency and post-transplant survival are pulmonary artery pressure, amount of oxygen needed at rest, age, body mass index (BMI), functional status, 6-minute walk distance, need for assisted ventilation, disease diagnosis, cardiac index and certain lab values.

In addition to the base points for medical urgency and projected survival, candidates may receive 20 bonus points if they are under the age of 18 years at the time of listing, or 5 points if they are a previous organ donor themselves (such as having donated a kidney or partial liver).

Transplant candidates can be given up to 5 points for their blood type (harder to match blood types will receive more

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AirWays

SERVICE THROUGH EDUCATION AND SUPPORT

AirWays is published three times per year by the Second Wind Lung Transplant Association, Inc. by and for lung transplant candidates, recipients, caregivers, and transplant professionals worldwide.

Every attempt is made to print accurate technical/medical information, but because of time and technical constraints it is not possible to check all submitted information.

Articles printed in this newsletter are for general information only and are not meant to be taken as professional medical advice. Each individual’s situation is different and information in the newsletter may or may not apply to you or your circumstances. It is your responsibility to discuss any information herein with your physician to determine whether it is beneficial or deleterious to your health.

We welcome contributions; however, we reserve the right to edit submissions for length and content. Any changes made will be reviewed with the author whenever possible.

To submit an article for publication in AirWays, send an MS Word document as an attachment to: phenry2ndwind@gmail.com.

To join or change your address please contact Second Wind via email to phenry2ndwind@gmail.com.

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

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President’s Notes
Tom Nate, President
Second Wind Lung Transplant Association, Inc.

Hello Members & Friends of Second Wind,

Those of us traveling the different stages of the Lung Transplant journey are all dealing with a variety of physical challenges, both pre and post-transplant, and some of the challenges can be quite difficult. There is no way to avoid it; the only path we can take to continue living is to tackle the challenges head on, with treatments, meds, doctors and more doctors, and a goal to keep on living, day to day, sometimes even hour to hour.

Along with the physical toll it takes on our bodies, the toll it takes on us emotionally and mentally can be equally challenging, if not more so. When our bodies are at their limit physically (and some of us may be in a condition of being bedridden, or very sedentary on oxygen and unable to care for ourselves at all), the mental stresses can be overwhelming. Yet it’s our attitude, our ability to handle these physical challenges, that is our biggest ally in trying to survive.

While I’ve been very blessed to have had very few physical challenges since my 2nd double lung transplant in 2010, I did have more than my share of physical battles. When on the list for that 2nd transplant, I spent three months in the ICU near death, and then 18 months living on an external vent.

During the toughest of these times, my wife and caregiver refused to let me get down or depressed. I did have days where that happened, but it never lasted long. I worked each day trying to live as normally as possible, riding a scooter to lunch at a nearby sandwich shop, and riding the four blocks to the hospital each day for rehab in sun, rain, or snow. I resolved to push through each day no matter the odds.

Looking back, what made a huge difference was not only in how I lived, but in how my family lived each day alongside me. Keeping a positive attitude may be the toughest part of our transplant journey, but it is absolutely critical to giving us a better chance at survival, and my family carried more than their share of the load.

I was reminded of this part of my transplant journey while listening to a podcast interview with my good friend, and 18-year double lung transplant survivor, Carrie Gobble. She has lived with Cystic Fibrosis her entire life, and her post-transplant years have been filled with multiple issues and challenges, yet her attitude remains one of a fighter, determined to live her best life.

You’ll find Carrie’s story in this issue of AirWays, and I have also posted the link to the podcast on our Second Wind Facebook page (“Second Wind Lung Transplant Association, Inc”). I highly recommend your checking it out.

Many thanks to you, Carrie, for your continued willingness to share your inspiring story, and my best wishes to all of you throughout your personal transplant journey.

Breathe Easy!
Tom Nate, President

Editor’s Notes

• This issue of AirWays includes stories from two different views of the lung transplant process: one from a recipient’s point of view, and one from a member of a transplant program’s professional team. We think you’ll find them informative, each in their own way.

• We encourage others to share your own story. Personal stories, like the one that Tom Nate shared in his column this issue, help transplant recipients understand the potential challenges we face and how to deal with them.

• Another way transplant patients help each other is through the mentoring process, something that is discussed in a feature article in this issue. Second Wind partners with the Lung Transplant Foundation to enable patients to connect with a trained mentor. Look for their ad on the back cover for more information.

• Finally, are you a frustrated author/editor looking for a way to use your skills to help others? Renae Woods, my excellent co-editor, had to resign the position for personal reasons. Thus, we’re in need of someone interested in assisting with the production of AirWays. As a co-editor, you might research and write about new transplant treatments, help edit pieces submitted by others, and proof read copy. If interested, contact me at the address below and we can talk it over.

- Patrick Henry, Editor
Pheny2ndwind@gmail.com
points) and up to 5 points for their height because patients who are shorter or taller than average tended to get fewer offers in the past.

Candidates will also receive up to 5 points for their immune sensitization. A blood test called panel reactive antibody (PRA) is used to assess the general likelihood of a person’s immune system reacting to the general population through the presence of certain antibodies. So, people who have more antibodies match up with fewer donors. For example, if someone has a 0% PRA, they match with everyone, but if they have an 80% PRA, they only match with 20% of the population. Giving points to patients with a higher PRA will give them more access to offers.

The aforementioned factors combine to form the CAS sub-score which usually ranges from 18-22. Up to ten additional points may be added to a candidate’s CAS based on the distance from a particular donor to the transplant hospital. These proximity points are added to a candidate’s CAS when a match run is completed (the process in matching donors with recipients). This means that a person’s final CAS will vary with each organ offer. The purpose of these proximity points is to enhance efficiency in the donor lung transportation process.

Under the Continuous Distribution model, we should see increased fairness and access to organs by removing geographical boundaries that were previously in place, and adjusting for factors that limited potential matches in certain groups. Over the coming months, the CAS will be monitored to determine if it has been successful in improving equitable access to transplants. Through continuous distribution, our hope is that more lives are saved through the gift of lung transplantation.

Want to learn more? Ask your transplant center staff or go to unos.org and search under “Continuous Distribution”.

Tonya Yurjevic, BSN, RN is a Pre-Transplant Coordinator and Brian Keller, MD, PhD is Medical Director of Lung Transplantation at Massachusetts General Hospital/Harvard Medical School in Boston, MA.

Questions may be directed via an email to: MGHLungTransplant@partners.org.

Dr. Keller can also be found on Twitter at @LungTxDoc.

Transplant Center Search Capability

The Second Wind website (2ndwind.org) includes a new button on the home page which allows users to search for information on all of the Lung Transplant Programs in the U.S.

Clicking on the “Transplant Centers” button takes you to a screen where you can look for a transplant center in your home state, or any other state in the country.

Information on each center includes basic contact info (main phone number, street address and website link), as well as the names and phone numbers of the center’s medical staff, transplant coordinators and social workers.

You can also look there to see whether or not a center accepts Medicare, allows for re-transplants and accepts patients who have been listed at more than one center.

Unfortunately, we know that many of the centers’ information is out of date, and we are working on a project to update them.

For each center you will see a field labeled, “Date of Last Update”. This will enable you to determine how up to date the information is for that center.

NOTE: If you are on staff at a transplant center and find that your information has not been updated within the past two years, or contains errors, please contact Patrick Henry at phenry2ndwind@gmail.com and he will assist you in bringing your program’s info up to date.
Mary Ann Hardy, past Second Wind board member and Treasurer, passed away surrounded by loved ones on February 18, 2023.

Born on April 7, 1962, she was only 60 years old at the time of her passing.

Mary served on the Second Wind Lung Transplant Association, Inc. Board of Directors from 2006-2009. She was our Treasurer from 2008-2009. Mary was our resident expert regarding the Second Wind Membership Database, and volunteered to keep the database up to date, when needed, long after she left the board.

Mary received her double lung transplant on May 31, 2002, almost 21 years ago. According to Mary’s husband, Gary, “Mary really enjoyed going to music concerts. As a younger person she would go with her friends to see the big-name bands that would come to the concert venues in Southeast Michigan. Journey and Chicago were among a couple of her favorites.

“Mary had learned to play guitar as a teenager and had a beautiful voice. She didn’t like to perform around strangers but with only close friends around, we would all be singing with Mary playing and leading the band.”

Gary also said that “Over the years Mary had shared her transplant experience with many people that were post and pre-transplant. She wanted to help others whenever and wherever she could. She had such a kind heart, especially for all things in need.”

Gary went on to say that “Mary also loved flowers and gardening. Needing to be careful around dirt post-transplant, Mary would have our daughters and me help her do the flower planting after she chose which flowers she wanted, and how they should be arranged.

“Most of all Mary liked being a mom and then a grandmother. When her illness started in 2001 our daughters were 4 and 8 years old and Mary’s biggest fear was not being around to raise them and give them the love only a mother can give. Through the miracle of a successful transplant, she was able to raise her daughters through Girl Scouts, girls’ basketball and volleyball, boys, and college and the marriage of her oldest daughter. Two years ago, she was able to call herself ‘Gram’ when her granddaughter Claire was born. Mary cherished every precious moment, and we cherished her.

“Mary’s donor was an Amish man, and his family and the Amish community welcomed Mary, and accepted her as family. She was invited to weddings and funerals and we visited as friends whenever possible. Every year for 20 years Mary would put a “Memoriam” in the Amish newspaper for her donor and express her thanks for the cherished gift of life. Sometime it was a poem she wrote or a reference to her donor’s life or hers. She would think hard and write and re-write until each memoriam was perfect: that was Mary.”

Gary notes that in November 2019 Mary recorded a podcast regarding her meeting with the donor family, and what an incredible experience that was for her and them. You can listen to it by going to your internet browser and searching under “Mary Hardy—Meeting My Donor Family”. It is very enlightening because most transplant patients never get to meet their donor family.

Mary will be greatly missed by all of us. The Second Wind Lung Transplant Association extends its most heartfelt condolences to Gary, and to his extended family.
I think mine is a transplant story like no other. Though, to be honest, everyone’s is, because we are all different. And, while that can be reassuring, it can also be daunting and frustrating.

When I was three months old, I was diagnosed with Cystic Fibrosis (CF). With a life expectancy of sixteen years at that time, I can’t imagine what my parents felt, but they raised me like any other kid. Letting me play outside in the creeks and dirt, play sports at school, go to sleepovers and even making plans for my future. I was never taught to have the mindset that I had a chronic illness.

CF affects the whole body, but it mostly impacts the lungs, with an accumulation of thick mucus making it difficult to breathe, and creating a harbor for infection. It didn’t really begin to affect my lungs until my senior year in high school, when I had to quit the varsity basketball team due to reoccurring pneumonia. And it didn’t become a life threatening issue until about three years after I graduated college.

Getting through college was really difficult, and when beginning my senior year I needed to be on IV antibiotics a lot to fight off the infections that had made my lungs their lair. But, from a hospital bed in St. Louis, Missouri I faxed my final accounting project to my professor and heard back a couple days later that I had received my BS in Accounting and was officially a graduate! I had made it!

I was able to work a few years in the CPA industry as an auditor until my doctors told me I needed to resign in order to take care of myself. My work life and physical health were in a cycle of catch twenty-two. I needed work for insurance and to pay for my medical bills, but work was causing me to be hospitalized.

While my friends were excelling in their careers, getting married and starting families, I felt tired and so alone, The social worker with the transplant program suggested I talk to someone who has lived through a transplant and can talk you through what to expect. In other words, a mentor. She told me she had the “perfect” mentor for me, and a couple weeks later I received a call from Gary Gobble, who received his bilateral lung transplant for CF. I called him and we talked about life with CF: difficulties of navigating IVs with college classes, work demands, and how being put on oxygen was a humiliating but necessary evil. It was strangely exciting...
that we had so much in common. I found new hope for a life after transplant and felt less alone. Gary suggested we meet so I could literally see what he looked like after transplant.

The very first thing I thought when he walked to my door was “He’s cute!” But I kept that to myself and welcomed him into my parents’ house, where we talked about transplants. Gary took time to talk to my parents and answer their questions. Since we lived close to one another, Gary and I visited with each other a few times over the course of the summer of 2004. We really got along well, having so much in common and he brought laughter in a time that was difficult to bear. Waiting for a lung transplant can be overwhelming. I felt lonely, depressed, and humiliated by the fact that I couldn’t do much of anything for myself anymore. But Gary helped me to feel accepted and understood, with no need to hide my illness or my feelings about it. To be open, to be vulnerable with another person was exactly what I needed. At some point that summer, he sat me down and we had a serious conversation about how he felt he couldn’t be my transplant mentor anymore because now he was my friend.

Every year my aunt and uncle would have a Halloween party, but no one in my family could take me and I was upset. Gary offered to come keep me company, to watch some movies and help keep me distracted. Then, in a turn of events that I can only describe as a miracle I got “the call” that very night while Gary was still with me, and my parents had just returned home.

After a successful surgery, and only nine days in the hospital, it appeared everything was going to be as I had hoped. And, to put a beautiful bow on top of the tremendous gift I’d received from my donor, Gary, my new friend and former mentor, asked me if I would be interested in dating, upon doctor approval of course!

I felt incredible. A new life. A new boyfriend. Breathing like I’d hadn’t experienced since I was seventeen. But then my transplant coordinator had bad news. I was in acute rejection and had several infections that needed to be treated, including a resistant strain of Cytomegalovirus (CMV) from my donor. In an unimaginable chain of events, I had several heart attacks and was in congestive heart failure due to all the IV medications to treat the CMV. I found myself in the ER being told I needed to be intubated in order to relieve my lungs fluid build-up. I was so scared. I didn’t know if I would ever come off the ventilator again, and my worst fears about the transplant were coming true.

My parents asked if I wanted them to call Gary. I said yes and when he got there, I apologized to him because I didn’t want to be a burden, his burden. We had only been dating for a few months and I didn’t want to let him see me like this. But I did, and I’m glad I did because it was in those trying moments that Gary said he really cared about me, and he wanted to be with me the rest of his life.

We married in November of 2005, exactly one year to the day we started dating. That was eighteen years ago.

The goal of my story is that it is crucial to relate to and feel seen and known by someone. I had been so independent for so long, that needing people felt like failure. What I needed to understand was how to allow myself to be loved. Allowing yourself to be loved, despite feeling like a broken, flawed, “sick” person, might be one of the hardest things you ever do. It was for me.

Our culture boasts individuality, but we are made, as humans, to depend on each other. We are social beings, in need of community. In need of each other. And, having someone to walk through my transplant journey with me meant everything.

I’m not saying that you’ll find love like I did, but I do know that having a mentor made the transplant experience easier to endure. And you may gain something even more than a mentor—a friend for life.
Remembering
Richard Wyatt

Richard H. ("Dick") Wyatt, former Second Wind Vice President and Treasurer, and a 23-year survivor of a double-lung transplant, passed away on Saturday, April 22, 2023, in Little Rock, Arkansas.

He was born February 12, 1945 in Blytheville, Ark. After graduating from Blytheville High School, Dick attended the University of Arkansas at Fayetteville and graduated in 1967 with high honors and a degree in accounting.

Dick was unusually intellectually gifted. Combined with his outgoing personality, his talents opened many doors for him. During his career he worked for IBM, and later became President of McClarty Leasing. In 1978, he formed a health electronic software company in partnership with Micky Lavender. He ended his career as Chief Information Officer for the Arkansas Department of Health and Human Services.

Musically inclined, Dick helped establish the Arkansas Repertory Theatre and performed in several of their earlier productions. Dick had an infectious smile and always cheered up a room with his arrival. He enjoyed spending time with his friends and family on Lake Hamilton, boating in the summer and attending Oaklawn Racetrack during the winter and spring.

In 1994 Dick came down with Pulmonary fibrosis, which is what led to his double lung transplant.

He joined Second Wind in 1996 and was elected to the Board of Directors in 1998. He was a valued member, serving in various capacities until 2002.

Dick is survived by his wife of 42 years, Olivia Nisbet Wyatt and their two children, Mary Alexander Wyatt and Olivia Owens Wyatt; and two children from his first marriage, Melanie Wyatt Brink (Darren) of Chicago, Illinois, and Richard (Rick) Wyatt of Little Rock.

Second Wind wishes to express our sincere condolences to Olivia and all the members of Dick’s extended family.

Tale of Transplant Recipient’s Gratitude

Awarded Grammy “Song of The Year”

Bonnie Raitt’s song, “Just Like That”, which just won a Grammy, tells the story of a stranger who shows up on the doorstep of a woman who has never stopped blaming herself for the death of her son, and reveals the healing power of connection.

The lyrics speak for themselves:

“Excuse me, ma’am, maybe you can help, the directions weren’t so clear
I’m looking for Olivia Zand, they said I might find her here”
Well, I looked real hard and asked him, “What she’s got he’s looking for?”
Said, “There’s somethin’ I think she’d wanna know” and I let him in the door
And just like that, your life can change if I hadn’t looked away
My boy might still be with me now, he’d be twenty-five today
No knife can carve away the stain, no drink can drown regret
They say Jesus brings you peace and grace, well, He ain’t found me yet
He sat down and took a deeper breath, then looked right in my face
I heard about the son you lost, how you left without a trace
I’ve spent years just tryna find you so I could finally let you know
It was your son’s heart that saved me, and a life you gave us both
And just like that, your life can change, look what the angels send
I lay my head upon his chest and I was with my boy again
Well, I’ve spent so long in darkness, I never thought the night would end
But somehow, grace has found me, and I had to let Him in
Not all transplant recipients are fortunate enough to connect with their donor family, but the sentiments conveyed in this song are something we can all appreciate.
My name is Staci Carter and I am a post-Lung Transplant Coordinator with The Ohio State University Wexner Medical Center in Columbus, Ohio. I have been a coordinator for almost 17 years, and have had the privilege of working with hundreds of patients and their families. I worked as a pre-transplant coordinator in the past, but my focus has been with the post-transplant patients for the last six years, and so I know this journey quite well.

One of the most important things to know is that we want all of our patients to have a successful transplant journey! Every single one of you is different, and the post-transplant ride is never going to be exactly the same for any two patients.

As a coordinator, it is my job to get to know my patients and their families and establish trust in our relationships. If we have trust and communication—which goes both ways—then I can trust that you (or your caregiver) will call me when you are having an issue or new symptom, and you will trust that I will use my experience and expertise to help you with whatever it is you are going through.

Your transplant coordinator is the one person among your medical team who knows you the best, and I have had different relationships with different patients and their caregivers. I have patients I need to approach and present information more gently, and there are some patients I can just say “Hey, what in the world are you thinking?” Trust also involves giving permission to loved ones and caregivers to be able to “anonymously” call to let me know that I need to follow up with the patient because something isn’t right.

Unfortunately, the reality is that not every journey is successful, and just as we are there in the good times and celebrations, we are also there with patients in the more difficult times. My patients know that even if I can’t always make it better, I will talk with you, sit with you, hold your hand, give you a hug, and explain things to your caregivers and loved ones in a way that helps them to understand what you are going through.

“TRANSPLANTATION CAN BE SCARY AND OVERWHELMING...AND)...IT IS AN HONOR TO HELP PEOPLE GO THROUGH THIS PROCESS.”

I have been asked quite a bit if I get attached to my patients and the answer is yes. The relationships are what I appreciate most in this role. Transplantation can be scary and overwhelming, but it can also be happy, amazing and rewarding. It is an honor to help people go through this process. I love seeing pictures of children, grandchildren, pets, vacations, and other experiences you wouldn’t have had without the amazing gift of life from your donor!

I love celebrating “lungaversaries” and reflecting on how far you’ve come. I enjoy helping you return to the activities and hobbies you love, and how to do them safely to protect your lungs. I also love hearing from the friends and families about the difference they see in you, even if it’s just watching you climb a flight of stairs without stopping.

On the other side of this, I also appreciate the opportunity to be there when the end of life is near. I have held the hands of many patients when they have taken their last breaths, and hugged many families at the funerals of our patients. It never gets easier and, as a coordinator, we hope we did our best to take care of them and their families. To this day, I still am in contact with families of past patients and look forward to events where we can reconnect, like the Pinwheel Planting we do at the beginning of April every year at our hospital.

I love being a lung transplant coordinator and couldn’t imagine doing anything else!
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 Kathryn Bryan
Sheryl Helt

In Memory of Dan Slone
Travis Cleland
Ladonna Gleespen

In Honor of Jane Kurz
Chuck Schuele

In Memory of Terri Downs
Brenda Eardley
Danny McRae

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Erin McMillan
John Monroe
Larry Roberts
Stephen Rousseau
Briana Ruhl
Cindy Wage
Katherine Ward
John Holt

In Memoriam

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

Marla Brown
Pre-Transplant

Kathryn Bryan
Transplanted 2016

Mary Hardy
Transplanted 2002

Richard “Dick” Wyatt
Transplanted 2016

NEW MEMBERS

The following individuals became members of Second Wind during the period February – June 2023. We welcome and thank you for your support of our mission.

Steven Bahm
Ashley Bates
John Becker
Benjamin Calimbas
Tammy Cooper
Brenda Eardley
Kelly Harden
Catherine Johnson
Jean Johnston
Kathleen Keiser
Jill Kenny
Julie Kobler
Linda Mayhew
Patty McClinton
Dawn McCreery
Craig Mekvold
Erica Miller
Stuart Miller
Michael Molina
Brittany Murray
Jim Oldfield
James Quain
Jasmine Rodriguez
Tammy Stafford
Lisa Stokes
Carly Streiff
Paula Yakes
Transplant Anniversaries

Some call it their “lungaversary”, some call it their “rebirthday”, or simply their transplant anniversary. Regardless of what they call it, survivors of a lung transplant always remember the day they received their new lung(s). On that day we stop to say a silent prayer of thanks to the courageous and unselfish donor family that made this gift of life a possibility.

### FEBRUARY 2023

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

Second Wind Lung Transplant Association, Inc.
75 Scattertree Lane
Orchard Park, NY 14127
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<<Addressline1>>
<<City>>, <<State>> <<Zipcode>>