



AirWays

SERVICE THROUGH EDUCATION AND SUPPORT

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EDITOR'S NOTE

We are looking for articles and photographs from lung transplant patients, caregivers, & lung transplant professionals. Personal experiences and clinical or treatment subjects are welcome.

To submit corrections, letters to the editor, photographs, and articles, send an e-mail to: schumann10.ss@gmail.com

Thank you!
The Editor

Treatment and Prevention of Infections Caused by 'Super-Bugs:' What You Need To Know

Natasha N. Pettit, PharmD, BCPS (AQ-ID)

Zhe Han, PharmD, BCPS

Department of Pharmacy, University of Chicago Medicine

Introduction

Patients that are receiving immune-suppressive therapy (e.g. tacrolimus, corticosteroids, cyclosporine, mycophenolate, etc.) that organ transplant recipients receive to prevent organ rejection, are instructed by their physicians to limit potential exposure to infections. This is particularly important for patients receiving these medications given the resulting reduced ability to mount an immune response to allow the body to rid itself infection if exposed.



Natasha N. Pettit

While all infections are a concern when patients may have a suppressed immune system, of particular concern are infections caused by microorganisms that are difficult to treat, highly transmissible, and/or are associated with infection reoccurrence. Such organisms are sometimes referred to as 'super bugs'.



Zhe Han

What are 'super-bugs?'

For the purpose of this brief overview, 'super-bugs' are infectious microorganisms that are particularly difficult to treat and often resistant to many commonly used antibiotics, easily spread from one person to another, and/or associated with reoccurrence of infection. Here we will review the pathogens that are problematic from an antibiotic resistance perspective (Table 1, page 6) and also *Clostridium difficile* which is more so problematic from the perspective of how easily it can be spread from person-to-person and its association with recurrent infections.¹

What is all of the concern over these 'super-bugs' about?

Antibiotic resistance has become a significant concern with at least 2 million patients each year acquiring infections that are resistant to at least one antibiotic, according to a recent

(Please see **Super-bugs** continued on page 6)

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AirWays

AirWays is published six times per year (if enough material of interest is submitted or found) by Second Wind Lung Transplant Association, Inc. by and for lung transplant candidates, recipients, caregivers, and transplant professionals worldwide.

We welcome all contributions to the newsletter; however, we reserve the right to edit submissions. Articles printed in *AirWays* are the property of Second Wind Lung Transplant Association, Inc. and may not be reprinted without permission from the Board Executive Committee.

We appreciate our members' help in obtaining donations to support Second Wind Lung Transplant Association.

General Information

Membership in Second Wind includes a subscription to *AirWays*. To join or change your address please contact Second Wind via postcard, toll free phone, or e-mail listed below.

A Word of Caution

Every attempt is made to print accurate technical/medical information from reliable sources. We would not knowingly present erroneous 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 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 circumstance. It is your responsibility to discuss any information herein with your physician to determine whether it is beneficial or deleterious to your health.

To submit an article for publication in *AirWays*, send an MS Word document as an attachment to:

schumann10.ss@gmail.com

Send hardcopy submissions to the editor:

Steve Schumann
1020 S. Gull Court
Palatine, IL 60067

For more information contact:

Second Wind Lung Transplant Association Inc.
2781 Chateau Circle
Columbus, OH 43221
Toll free: 1-888-855-9463
E-mail: keelerc768@aol.com

President's Notes

Cheryl A. Keeler, President
Second Wind Lung Transplant Association, Inc.

Happy New Year! The Board of Directors hopes that all of you enjoyed a wonderful beginning to 2015 and that health and happiness follow you throughout the months ahead. Our first Board meeting of the year was held on January 6, 2015. Listed below is an update on the activities of your Board of Directors.

Board Members

We are pleased to announce the addition of one new Board Member. Mr. Ross Pope from Crescent Springs, Kentucky, was elected to the Board on January 6, 2015. Ross agreed to serve a three year term. He brings a tremendous amount of business experience to the Board in areas that include marketing, advertising and fund raising, as well as other business experience as outlined in Ross's biography which can be found starting on Page 10 in this edition of *AirWays*. One of the most important attributes Ross brings to the Board is his commitment to give back to the transplant community. Ross is dedicated to helping our members in any way he can. We welcome him to the Board and look forward to working with him.



Director Julie Martin also agreed to serve an additional three year term. Julie is your Peer Support Program Coordinator and also the E-mail Support Group Coordinator. Through both of these programs, Julie is in almost daily contact with the membership. The work Julie does for Second Wind is invaluable. Thank you Julie for all that you do for

Second Wind.

AirWays

Please note that this issue is actually a compilation that spans November 2014 through February 2015, so it will contain more material than usual. We will return to publishing every two months with the March-April issue. Thank you to Member Carole Gibson Morton for submitting her transplant story which was published in the previous issue of *AirWays*. I'm sure we all agree that it is encouraging and uplifting when we read about another member's journey. We are all looking forward to the second half of Carole's story which appears in this current issue. If you are willing to tell your transplant story, please contact our Editor and fellow Board Member Steve Schumann at schumann10.ss@gmail.com.

Website Redesign

Work continues on our new redesigned web-site. The design firm is preparing a demo site for the Board of Directors to

(Please see *President's Notes* continued on page 3)

review in the next few weeks. All information contained on the web site will be reviewed for accuracy and to make certain it is up-to-date. We expect work to be concluded during the first quarter of 2015, with a launch of the new site this upcoming Spring.

Financial Assistance Program

Due to your generous donations supporting the Financial Assistance Program, we were able to provide \$2,108.79 to our members in 2014. The grants awarded to our members helped with transportation costs, temporary housing and other expenses not covered by insurance. Thank you all for your support of this much needed program. Information about the Financial Assistance Program can be found on our web site: www.2ndwind.org or by calling our toll-free Help Line at: 1-888-855-9463.

Transplant News

• United for UNOS - 5K & Fun Run

UNOS is hosting this first annual event, a 5K and Fun Run, which is a family friendly walk/run to honor organ donors, celebrate organ recipients and to offer hope to those who continue to wait for a lifesaving organ transplant. The event will take place on Saturday, April 11, 2015 at 4951 Lake Brook Drive, Innsbrook, VA (Near Innsbrook After Hours Pavilion) The Fun Run begins at 6:00 p.m. with the 5K run beginning at 6:30 p.m. Proceeds from the event will support UNOS' lifesaving work, including organ matching and transplantation education programs. Information regarding the event and registration can be found at: http://www.unitedforunos.org/docs/5K_Course.pdf or by contacting Michelle Tolliver at 804-782-4865.

• Potential for inhalable vaccines for influenza, pneumonia, with new approach.

Adapted media release - Researchers at the University of North Carolina at Chapel Hill and North Carolina State University have uncovered a novel approach to creating inhalable vaccines using nanoparticles that shows promise for targeting lung-specific diseases, such as influenza, pneumonia and tuberculosis. The findings published in the *Proceedings of the National Academy of Sciences*, also have broad public health implications for improving the accessibility of vaccines. An inhalable vaccine may eliminate the need for refrigeration, which could improve shelf life, but also enable distribution of vaccines to low-resource areas, including many developing countries where there is significant need for better access to vaccines.

• Study shows how vulnerable our genetic machinery can be to air pollution

According to researchers at the University of British Columbia and Vancouver Coastal Health, just two hours of exposure to diesel exhaust fumes can lead to fundamental health-related changes in biology by switching some genes on, while switching others off. The study, published this month in *Particle and Fibre Toxicology*, examined how such exposure affected the chemical "coating" that attaches to many parts of a person's DNA. The coating, called methylation, can silence or dampen a gene, preventing it from producing a protein - sometimes to a person's benefit, sometimes not. How these changes in gene expression translate to health is the next step for researchers. But this study shows how vulnerable our genetic machinery can be to air pollution, and that changes are taking place even if there are no obvious symptoms. Dr. Chris Carlsten of the University of British Columbia, stated "any time you can show something happens that quickly (within two hours of exposure), it means you can probably reverse it - either through a therapy, a change in environment, or even diet."

We are all looking forward to 2015 and wish you all health and happiness in the days ahead.



JUST A REMINDER

With regard to the announcement in the last issue of *AirWays*, please follow these guidelines when purchasing items on-line. There are other organizations that have Second Wind in their name, so please choose: Second Wind Lung Transplant Association Escondido, CA when ordering online using iGive.com.

When ordering on Smile.Amazon.com please choose Second Wind Lung Transplant Association Columbus, Ohio This will ensure that your support is credited to us.

Thank you,

Julie Martin

Director Second Wind Lung Transplant Association, Inc.



Food Safety for Transplant Recipients

Second Wind is pleased to share excerpts from the educational brochure "Food Safety for Transplant Recipients", published by U.S. Department of Agriculture (USDA), Food Safety and Inspection Service (FSIS) in September 2006, slightly revised September 2011, Both agencies are divisions of the U.S. Department of Health

(Please see *Food Safety* continued on page 5)



After Lung Transplants, Resistance to Anti-Viral Drug May be More Likely in Cystic Fibrosis Patients

Loyola Study Suggests CF Patients Require Close Monitoring for Resistance to Ganciclovir

MAYWOOD, Ill. (Dec. 18, 2014) – A drug called ganciclovir is given to lung transplant patients to protect against a life-threatening virus that is common after transplantation.

Ganciclovir reduces mortality due to the virus from 34 percent to between 3 and 6 percent. But between 5 percent and 10 percent of patients infected with the virus have strains that are resistant to the drug.

A Loyola University Medical Center study found that such resistance may occur more frequently in cystic fibrosis patients. These patients were found to have insufficient levels of the drug in their bloodstream, enabling the virus to continually replicate. This in turn may increase the chance that mutations will occur and result in drug resistance.

The study suggests that cystic fibrosis patients should be monitored to ensure there are therapeutic levels of ganciclovir in their bodies, said James Gagermeier, MD, first author of the study. The study is published online ahead of print in the journal *Transplant Infectious Disease*.

Lung transplant patients take immune-suppressing drugs to prevent rejection of their new lungs. But suppressing the immune system makes the patient more vulnerable to a virus called cytomegalovirus (CMV).

Gagermeier and colleagues reviewed records of 51 Loyola lung transplant patients. Twenty-one patients had CMV infection. Ten of these infected patients responded well to ganciclovir, meaning the virus was eliminated and symptoms improved within 14 days. Of the remaining 11 patients, 6 patients with sufficient levels of ganciclovir experienced a delayed (longer than 14 days) but appropriate response to the drug. Five patients with insufficient levels of ganciclovir did not respond to the drug; all five of these patients had drug-resistant strains of the CMV virus.

Four of the five patients who did not respond to ganciclovir (80 percent) had cystic fibrosis. By contrast, only 2 of the 16 patients who responded to the drug (12.5 percent) had cystic fibrosis.

Cystic fibrosis patients lack pancreatic enzymes that facilitate the absorption of food and medicines. They also clear drugs out of the body more quickly, Dr. Gagermeier said.

Results of the study suggest that cystic fibrosis patients who have had lung transplants should be closely monitored to ensure they have adequate levels of ganciclovir in their blood stream, Dr. Gagermeier said.

The study has limitations. It is a retrospective study with a small sample size, and patient compliance with the antiviral medications was not systematically evaluated. Thus it's possible that poor compliance may have contributed to infection with CMV and/or resistance to ganciclovir. Importantly, genetic analysis was not performed on all patients with CMV infection, and therefore cases of ganciclovir resistance may not have been detected.

The study is titled "Subtherapeutic ganciclovir (GCV) levels and GCV-resistant cytomegalovirus in lung transplant recipients."

Dr. Gagermeier is medical director of pulmonary medicine and an associate professor in the Division of Pulmonary and Critical Care Medicine of Loyola University Chicago Stritch School of Medicine. Co-authors are Joshua Rusinak, PharmD, Nell Lurain, PhD, Charles Alex, MD, Daniel Dilling, MD, Christopher Wigfield, MD and Robert Love, MD.

(Reprinted with kind permission of Loyola University Medical Center, Maywood, IL. For further information please contact Jim Ritter, Media Relations, jritter@lumc.edu, (708) 216-2445)

Notice: It is the Policy of Second Wind Lung Transplant Association, Inc. to prohibit the posting of any email and/or message regarding the exchange of medications on any communication medium of the Association.

(*Food Safety continued from page 4*)

and Human Services and the Food and Drug Administration. USDA and FSIS have kindly granted permission for Second Wind to reprint excerpts from this publication. All the information is reproduced verbatim with no editorial changes.

As editor of AirWays it is not my intention to completely reproduce the publication as there are some “busy” charts and color graphics that may be beyond my skills to carry out. Rather, as space permits with each issue I will choose some interesting material to print. The publication is available at no charge by calling 1-888- MPHOTLINE (1-888-674-6854). You can also E-mail mphotline.fsis@usda.gov or fsis.outreach@usda.gov.

But wait, there’s more! Second Wind has acquired a limited number of pamphlets and we are pleased to offer them on a first come basis; when they are gone, they’re gone. You can contact the editor, preferably by E-Mail, but snail mail can also be submitted to: schumann10.ss@gmail.com, or Steve Schumann, 1020 S. Gull Court, Palatine, IL 60067.

The first selection comes from the opening pages of the pamphlet and provides some background information on Food Safety. Most transplant recipients have been educated at their transplant center about this information. More specific details will be highlighted in future issues.

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FOODBORNE ILLNESS IN THE UNITED STATES

When certain disease causing bacteria, viruses or parasites contaminate food, they can cause foodborne illness. Another word for such a bacteria, virus, or parasite is “pathogen”. Foodborne illness, often called food poisoning, is an illness that comes from a food you eat.

- The food supply in the United States is among the safest in the world—but it can still be a source of infection for all persons.
- According to the Centers for Disease Control and Prevention, 48 million persons get sick, 128,000 are hospitalized, and 3,000 die from foodborne infection and illness in the United States each year. Many of these people are children, older adults, or have weakened immune systems and may not be able to fight infection normally.

Since foodborne illness can be serious—or even fatal—it is important for you to know and practice safe food-handling behaviors to help reduce your risk of getting sick from contaminated food.

FOOD SAFETY:

IT’S ESPECIALLY IMPORTANT FOR YOU

As a transplant recipient, you are probably familiar with the topic of transplant rejection. It’s the body’s natural reaction or immune system’s response to “foreign invasion.”

- A properly functioning immune system will try to reject or destroy your new solid organ and/or bone marrow transplant—in the same way that your immune system works to clear infection from your body.
- Because of this natural rejection possibility, it’s common for transplant recipients to take medications to keep rejection from happening. These drugs are called immunosuppressive medications because they suppress your immune system to keep it from attacking, or rejecting, your transplanted organ or bone marrow. Over the past few decades, substantial progress has been made in the development of these drugs that help prevent you from experiencing a transplant rejection.
- Immunosuppressive medications are important, as they can protect your transplanted solid organ and/or bone marrow. But a side-effect of these immunosuppressants is that they leave you more susceptible to developing infections—like those that can be brought on by disease-causing bacteria and other pathogens that cause foodborne illness.
- Because you are a transplant recipient, you are more likely to have a lengthier illness, undergo hospitalization, or even die should you contract a foodborne illness.
- To avoid contracting a foodborne illness, you must be especially vigilant when handling, preparing, and consuming foods.

**MAKE SAFE FOOD HANDLING A LIFELONG COMMITMENT
TO MINIMIZE YOUR RISK OF FOODBORNE ILLNESS.**

**BE AWARE THAT AS YOU AGE, YOUR IMMUNITY
TO INFECTION NATURALLY IS WEAKENED.**



TABLE 1:

Resistant Pathogen	Number of Infections/year ¹	Antibiotics Affected
Drug-resistant <i>Streptococcus pneumoniae</i> (DRSP)	1.2 million	Beta-lactams (penicillin, amoxicillin/ampicillin), macrolides (e.g. azithromycin)
Methicillin Resistant <i>Staphylococcus aureus</i> (MRSA)	80,461	Beta-lactams (e.g. oxacillin, nafcillin, cefazolin)
Extended spectrum beta-lactamase (ESBL+) <i>Enterobacteriaceae</i>	26,000	Beta-lactams (e.g. cefepime, ceftriaxone, penicillin, ampicillin, etc.) Carbapenems or fluoroquinolones can be used to treat
Vancomycin resistant <i>enterococcus</i> (VRE)	20,000	Vancomycin
Carbapenem resistant <i>Enterobacteriaceae</i> (CRE)	9,300	Resistance to nearly all available antibiotics. Only options for treatment include: colistin, aminoglycosides, tigecycline.
MDR <i>Acinetobacter</i>	7,300	Beta-lactams (e.g. ampicillin-sulbactam), Colistin
MDR <i>Pseudomonas</i>	6,700	Beta-lactams, aminoglycosides, fluoroquinolones

MDR: Multi-drug resistant, Beta-lactams (includes cephalosporins (e.g. ceftriaxone, cefepime, cefazolin), penicillin, ampicillin/amoxicillin, piperacillin, carbapenems (e.g. meropenem, ertapenem, doripenem), monobactam (e.g. aztreonam))

report from the Centers for Disease Control and Prevention (CDC).¹ Infections caused by resistant bacteria create a challenge in selecting the most optimal antibiotic regimen for patients, especially when few antibiotic options are available that would have activity against the organism. With only 22 antibiotics being developed between the years of 2000 to 2012, there are limited antibiotic options to select from. As a result, more complex regimens or antibiotics associated with greater toxicities may need to be employed. Despite initiation of antibiotics, patients infected with antibiotic resistant pathogens do not always respond to therapy adequately. Unfortunately, approximately 23,000 patients die each year secondary to antibiotic resistant infections. Antibiotic resistance not only makes managing infections more difficult it also negatively affects healthcare resources, with an estimated economic burden of 20 billion dollars in excess healthcare costs.

Clostridium difficile (*C. difficile*) is a spore-forming bacterium that is the most common cause of antibiotic-associated diarrhea. The organism is responsible for 337,000 infections and 14,000 deaths every year in the United States.² While antibiotic-resistance is extremely rare in *C. difficile*, it is still considered a superbug because of the severity of diseases it can cause and its tendency to recur even after it has been appropriately treated. In addition to watery diarrhea, *C. difficile* may lead to serious diseases including colitis, perforation of the colon,

sepsis and death.

Who is at risk for infections cause by these ‘super-bugs’?

While antibiotic resistance can occur in any patient population, those at the greatest risk for developing infections caused by antibiotic resistant organisms include patients receiving chemotherapy, that have undergone complex surgeries, those with rheumatoid arthritis, if receiving chronic dialysis, and those that have undergone solid organ or bone marrow transplantation. These patient populations are also the most challenging to manage given their already reduced ability to fight an infection as their immune response is blunted.

A weakened immune system also increases risk for *C. difficile* infections in transplant patients. Other risk factors include long length of stay in healthcare settings, exposure to antibiotics for treatment or prevention of infections, use of proton pump inhibitors, and older age.

What resistant pathogens/organisms are there?

The commonly encountered and/or severe antibiotic resistant pathogens in clinical practice include: Methicillin Resistant *Staphylococcus aureus* (MRSA), Vancomycin resistant *enterococcus* (VRE), Extended spectrum beta-lactamase

(Please see **Super Bugs** continued on page 7)

(*Super Bugs* continued from page 6)

(ESBL+) producing Enterobacteriaceae, Carbapenem resistant Enterobacteriaceae (CRE), multi-drug resistant *Pseudomonas aeruginosa* and *Acinetobacter*, and drug-resistant *Streptococcus pneumoniae* (DRSP). Table 1 lists the relative incidence of these infections according to the CDC, and also indicates the antibiotics most affected.

What are current treatment options for these ‘super-bugs?’

The treatment options for resistant organisms vary and based on which antibiotics are found to be active against the organism based on laboratory provided information (referred to as antibiotic susceptibilities). There are several antibiotics that are active against a wide variety of organisms, the most commonly used antibiotics for infections caused by resistant organisms include carbapenems, later generation cephalosporins (e.g. third and fourth generation), beta-lactam with beta-lactamase inhibitors (e.g. piperacillin-tazobactam), vancomycin, daptomycin, linezolid, colistimethate-methanesulfate (colistin), and aminoglycosides. Which antibiotics are initiated is based on the reported antibiotic susceptibilities of the organism, other organisms that may also be present at the same time, the patient’s clinical status, and careful consideration of any drug-interactions or toxicities. Therefore not every antibiotic regimen will be the same for every patient with infections caused by these organisms as it is often patient-specific.

C. difficile infections are treated with antibiotics, including metronidazole, oral vancomycin, or fidaxomicin. Treatment is continued for at least 10 days and other antibiotics should be discontinued if possible. One problem with *C. difficile* treatment is that infection returns in about 20 percent of patients and transplant patients, given their weakened immune system is at higher risk for recurrent *C. difficile* infections. The first return of *C. difficile* infection can be treated with the same antibiotics used for primary infection. Future infections should be managed with oral vancomycin or fidaxomicin. In a small number of patients, *C. difficile* infections return multiple times and may be debilitating. Transplanting stool from a healthy person to the colon of a patient with repeat *C. difficile* infections has been used with success. These “fecal transplants” appear to be the most effective method for managing repeat *C. difficile* infections but their long term safety has not been established.

What can we do about antibiotic resistance and the spread of *Clostridium difficile*?

The most important interventions or ways that antibiotic resistance can be prevented is through preventing the spread of these pathogens through infection control practices (e.g. hand hygiene and contact precautions such as limiting contact

and use of barriers such as gloves and gowns) and improving antibiotic prescribing practices (e.g. only prescribing antibiotics when needed for an appropriate amount time). Patients and prescribers alike should be conservative with their antibiotic use, asking for or prescribing antibiotics only when treating bacterial infections. It will also be pertinent for the development of new antibiotics so that when patients do have drug resistant infections, there are adequate options to select from. Additionally, many infections may be preventable by vaccination, therefore patients should ensure that all necessary vaccinations are up-to-date.³

C. difficile is shed in feces and its spores can live for a long time outside of the human body. Surfaces, devices, and other materials may become contaminated, serving as a reservoir for *C. difficile* spores. These spores are then transferred to patients mainly via the hands of healthcare workers who touch these surfaces and then patients.²

To prevent *C. difficile* infections, doctors, nurses, and other healthcare workers should:

- Clean their hands with soap and water or an alcohol-based hand rub before and after caring for every patient.
- Clean hospital rooms and medical devices that have been used with patients with *C. difficile* infections.
- Use contact precautions to prevent *C. difficile* from spreading from one patient to the other. These “contact precautions” consist of many practices and some of the most important ones include wearing gloves and gowns and washing their hands with soap and water that physically removes *C. difficile* spores.

Patients and their families are empowered to prevent *C. difficile* infections when admitted to the hospital. Patients should make sure that healthcare workers taking care of them practice good hand hygiene. If patients do not see them clean their hands, it is encouraged that they ask them to do so. The risk of patient visitors getting *C. difficile* infections by visiting patients in the hospital is low; however, they should still clean their hands before they enter the room and as they leave. Individuals entering and leaving a patient’s room that is infected with *C. difficile* should always be wearing gloves and a disposable gown.

For patients who develop *C. difficile* infections in the hospital, their diarrhea is usually resolved or much improved by the time they go home and as such, the risk of giving the infection to their family members when they go home is low. However, if patients develop *C. difficile* infections, there are still many things that should be done to decrease the risk of repeat infections and protect others:

(Please see *Super Bugs* continued on page 8)

(*Super Bugs* continued from page 7)

- If given a prescription for an antibiotic to treat *C. difficile* infections, it should be taken as prescribed.
- Wash hands often, especially after going to the bathroom and before preparing food. Family members in the same household should as well.
- Wear disposable gloves if expected to come into contact with stool, urine and wound drainage. Wash hands after removing gloves.

Clean areas of the home, such as the bathroom, frequently with a bleach-containing cleaner.

- Change and wash clothes and linens on a regular basis, or any time they are soiled.
- If diarrhea occurs after leaving the hospital at home, patients should report this to their healthcare providers immediately.

References:

1. Centers for Disease Control and Prevention. Antibiotic Resistance Threats in the United States, 2013. <http://www.cdc.gov/drugresistance/pdf/ar-threats-2013-508.pdf>
2. Centers for Disease Control and Prevention (July 9, 2014). Emerging Infections Program- Healthcare-Associated Infections Projects Fact Sheet. <http://www.cdc.gov/hai/eip/pdf/Cdiff-factsheet.pdf>
3. Centers for Disease Control and Prevention (July 22, 2010). Protecting Yourself and Family. Antibiotic/Antimicrobial Resistance. http://www.cdc.gov/drugresistance/protecting_yourself_family.html

My Post-Transplant Story

Carole Gibbons Morton

It's unusual for that first call to be the only call so I knew I was lucky; I just didn't know my luck would continue way beyond expectation."

That was the last line of my first installment of my double lung transplant ("My Transplant Story", published in *AirWays* Volume 23, No. 4) which I received August 20, 2003 due to Alpha-1 Antitrypsin Deficiency Disorder. It's been over 11 years since then and my good fortune continues to this day in spite of a few setbacks.

I received the lungs of a 15-year-old girl; it was a perfect

(Please see *Post-transplant Story* continued on page 9)

The Rest of My Life

Diane Tefft Young, MA, LICDC, MAC

The "call" came one autumn Saturday night as I was attending a fiftieth reunion party with a friend, his classmates, and their wives. I had anxiously waited seven weeks on the UNOS (United Network for Organ Sharing) transplant list for the call. During that time I attempted to organize my life so that I could be gone from home for as long as three months. My transplant hospital bag was packed, I saw myself as being ready for this important step which was the only way I would survive.

As my forty year old son and I were speeding up interstate 71 on our way to the Cleveland Clinic during the early morning hours of October 10, 2010, he turned to look at me and inquired, "Mom, what



do you think you will do with your life once you receive your transplant?" I was working part time as an addiction counselor and despite being exhausted nearly all the time, I was simultaneously focused on doing everything I had been told to do to stay alive despite a recent rapid downward health spiral. It is challenging to be tethered to oxygen every minute of every day, but that is

how I survived. I hadn't even thought about the next step: **THE REST OF MY LIFE.** I had no reply to Andrew's provocative question. I was clueless.

We arrived at the Cleveland Clinic before dawn, 2:30 AM, 10.10.10. I moved swiftly through check-in, including insurance verification, and on to the surgery floor where I rapidly changed from my comfortable well-worn Calvin Klein jeans, t-shirt, and flip flops into a hospital gown. Within minutes I was lying flat on my back on a gurney as three different nurse/techs attempted one-by-one to begin an IV. I have my mother's "rolling veins" so this was a major challenge on this most important night of my sixty-eight years. Once the IV was successfully started, I was hurried out of this prep room and down the hall toward the wide double doors leading to the surgery suites.

Fortunately, my relatively uneventful right lung transplant surgery was successful. Within four weeks I was moving slowly, but at home in the suburbs of Columbus, Ohio. Six weeks after transplant, it was Thanksgiving and much to my surprise I had started to write and collect post-it notes about my pre- and post-transplant experience. I had just begun to crack the door opening to my new life and career.

(Please see *The Rest of My Life* continued on page 9)

Quickly, I accumulated a stack of forty or more post-it notes. I called long-time friend Gretchen and we arranged to meet at a coffee shop after church the following Sunday morning, a few days before Christmas. My plan was to ask Gretchen, an editor, where I could find a class for beginning writers. Many friends had suggested that I should write a short story or screenplay about my transplant experience which has been slightly altered here to protect the innocent.

Much to my enormous surprise, Gretchen suggested that I simply begin to write and that taking a writing class was unnecessary. I had always wanted to write for publication although my writing experience was limited other than fulfilling my master's degree requirement of writing a complicated thesis. I had also written a short story that was published in my high school's literary magazine. For my grandson Alex's fifth Christmas, I had written a take-off of the Night at the Museum book, featuring a life-size junk metal horse sculpture named Joseph who although living in a sun-filled courtyard within the museum during day, at night walks out of the building's side door to meet and to play with lawn sculpture animals in the adjacent garden.

Now, four years into "The Rest of My Life," I am gently becoming a writer. I have self-published one book, written a second manuscript about living an authentic, resilient, and joyful life while living with a chronic illness. I have begun to shop my manuscript to medium-sized publishers. I have spoken comfortably to any size group as I have promoted and sold my first book. I have also been on TV in an effort to support transplant. On several occasions, I have sold multiple copies of my transplant book to a large Ohio hospital followed by book signings at the same hospital's book store. I also wrote an article about the organ procurement process for this newsletter.

Recently, I was asked to become a member of both a literary critique group as well as a book club. I am involved with church as a Lay Eucharist Minister and also I have become a supportive congregant for St. Mark's Episcopal Church's "soft service" for handicapped (Alzheimer's disease and autism spectrum disorder) worship service attendees. I work out six days a week (Pilates-on-the-Reformer, floor yoga, and gym activities) and I generally follow the Mediterranean diet. I spend time with and continue to be completely charmed by my two early adolescent grandchildren, Alex and Katie. Although, I am intentional in how I live my life, I have been re-hospitalized twice (nocardia pneumonia, a still-undiagnosed food preservative allergy, and a now properly diagnosed and correctly treated heart diagnosis). At times, I struggle and stumble as I create my post-transplant life, yet I consistently feel grateful for the gift of life. I am acutely aware that transplant changes not only the existence of the one who receives the

transplanted organ but additionally impacts the lives of family and those who love and or care about the one that has received the transplant.

As I begin the new year, it would be impossible to close these thoughts without thanking the staff of the Cleveland Clinic lung transplant program and also expressing gratitude to an anonymous donor and her family. In your anonymity, a star sparkles and remains high in the night sky each and every night.

Diane received a single Lung Transplant at the Cleveland Clinic Foundation, 10.10.10. She is also the author of "Humbled by the Gift of Life: Reflections on Receiving a Lung Transplant", available on Amazon.

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(Post-transplant Story continued from page 8)

match. I was taken off the ventilator less than five hours post-transplant. I spent less than two full days in ICU and was released from the hospital to go home 200 miles away on Day Eight. I spent that first night at home alone, almost needing to pick up my mom and toss her out; she was determined to spend the night. I was so tired of being hovered over for months before transplant that I couldn't wait for a little peace and quiet, good breathing and to be, once again, alone and independent.

The first 11 months were fantastic. I had tremendous lung function, got out and did whatever I wanted and went wherever I wanted. Eleven months post-transplant I traveled to St. Louis



(less than 200 miles away) to stay with a friend who had a double lung transplant at Barnes. He was required to have someone with him at all times for the first six weeks. It's interesting how different some centers are; mine didn't have such rules and, in fact, I spent my first night at home alone.

I had tummy issues in St. Louis but we had a good time enjoying our successful transplants and we got out every day to see the sights. My third day there my mother called me home; my 80-year-old dad was in the hospital, in a coma, and not given much hope. I was on my way home within minutes. When I arrived at the hospital, he was receiving Last Rites. I spent the night in the waiting room along with my mom and sister. I still wasn't feeling 100%, but it was the least of my worries.

The next afternoon I went home and went straight to bed. Dad was still hanging on but not improving. I couldn't get out of bed. I didn't know what was happening but really didn't care since I felt so horrible. I have since figured out that when I
(Please see Post-transplant Story continued on page 11)

NOVEMBER 2014

<u>Name</u>	<u>Transplant Date</u>	<u>Yrs</u>
Carolyn Blaylock	11-5-2003	11
Richard J. Williams	11-5-2007	7
Cathy Cuenin	11-9-2004	10
Chuck Schuele	11-20-2008	6
Frances Lambert	11-24-2009	5
Henk A. Berends	11-28-2003	11
Bettina Irvine	11-28-2004	10

DECEMBER 2014

<u>Name</u>	<u>Transplant Date</u>	<u>Yrs</u>
Grace Bachmann	12-3-2005	9
Gage Georgeff	12-14-2009	5
Fred Walker	12-15-2006	8
Betsy Cichon	12-16-2004	10
Dave Griggs	12-27-2010	4

JANUARY 2015

<u>Name</u>	<u>Transplant Date</u>	<u>Yrs</u>
Paula Moscariello	1-1-1994	21
John McNamara	1-1-2006	9
Dennis Wright	1-9-2012	3
Karen Jacobson	1-12-2007	8
Michael Thomas	1-16-2012	3
Robert Klein	1-17-2010	5
Thomas Barbour	1-18-2011	4
Cathie Weir	1-21-2008	7

Congratulations to all who celebrate another milestone!

Ross Pope

Second Wind Welcomes New Director to Board

Born, raised and educated in the West, after graduating from BYU, I joined ADP and moved around until I met my wife of 36 years and we settled in the Greater Cincinnati area where we raised three daughters. After 32 years with ADP, we purchased a dry cleaning business and continue to operate it today.

My sister was diagnosed with IPF in 2006 and was fortunate to have been involved in a clinical study of pirfenidone that slowed the progress of her disease. She was transplanted in Dallas just five weeks ago.



I was the transplant pioneer in our family and after being diagnosed in 2012, my IPF progressed rapidly and I was transplanted 2/10/14 with a single right lung at the Cleveland Clinic. After 10 months I have resumed a pretty normal life, traveling, exercising and enjoying life. I am thankful for a donor and their family for the gift of life and hope to be able to help those who are going through the transplant

experience. If I can be a resource and help for others, I will feel that I have accomplished one of my goals.

I have served on several Boards of Directors, one being Dignity in Death, helping those who could not afford a decent funeral/burial for their loved one. We helped many families. The second board was Redwood Rehabilitation (www.RedwoodNKY.org) where the focus was assisting the handicapped individuals achieve their maximum potential. What a blessing to see non-verbal, paraplegic individuals learn to communicate and now use laser pointers and the internet to communicate with friends and family.

Having been involved providing service most of my adult life through heavy involvement in our church, I have served as the leader of a local congregation, providing counseling, financial assistance and spiritual direction.

It will be great to serve with 2nd Wind because I know what a great help and support it has been for me and our family. Our involvement in a fundraising effort yielded almost \$30,000 to help offset the expenses of the lung transplant.

I am truly thankful for my family that have been there as caregivers and a support through this journey, called a transplant. I believe in miracles and the power of prayer and look forward to serving wherever possible.

have even the slightest fever, I don't think straight at all. Later that night, when I knew my mom would be home from staying with Dad at the hospital, I called and asked her to come over. I felt terrible doing that to a 75-year-old woman but then again, I wasn't thinking clearly. She took my temperature – 103°. I remember telling her to call 911 and then I called my best friend to tell her I was going to the hospital. I also remember grabbing my purse and going to the living room to wait for the ambulance. It was sepsis and I was nearly dead.

I was put on life support and in a drug-induced coma. The hospital staff told my sister I had about a 5% chance of survival. Here I was at one hospital while my dad was at another hospital; the family had to split up with my sister being with me and my brother staying with Mom. My best friend really went to bat for me and got my transplant coordinator on my cell phone and had her communicating with the hospital. It took over two days but once I was stable enough, I was flown by helicopter to my transplant center 200 miles away. At that same time, my dad was a 'code blue' at the other hospital. Everyone was quite hysterical except for my dad and me who were safely in unaware comas. It escaped nobody's attention that we could die within minutes of each other.

The ending to that story is I spent nearly a month in the hospital and my dad recovered as well; both of us back to an active lifestyle. He lived another eight years, to the age of 88, dying eight days after my wedding which he had attended. I obviously inherited his tenacious spirit. The sepsis was eventually blamed on my chronic sinus infections over the years and as soon as I had recovered enough, I had sinus surgery (I would rather have a transplant any day!).

After that "bump in the road" I sailed along for years without any problems. In fact, eight years post-transplant I had my best lung function numbers. Then something very strange happened. I developed lymphedema in my right leg which ran up to my hip and waist. I was mortified and a deep depression set in that I still, to this day, struggle with. My leg swelled to almost twice its size, the skin becoming more like orange peel than skin, and a dark blackish-red color set in. My weight went up by 40 pounds in a matter of weeks. The worst part is there is no cure. Turns out it's a very rare side effect of Rapamune. I know of only one other person who developed lymphedema post-transplant and she has it in her arm but without the skin conditions.

By this time in my life I was committed to my future husband who could not have been any more reassuring and comforting during this difficult time. My transplant center hospitalized me on five different occasions trying everything to change the condition, but nothing worked. I now wrap my leg every day with a special compression wrap and I take a huge dose of Lasix. The swelling starts at the bottom of the foot so shoes

don't fit, slacks don't fit, and clothes just don't look good. I have had expensive, custom slacks made that still don't look good. Long skirts tend to show the leg wrap which goes to the ankle so I'm self-conscious about that as well. I use sneakers as compression shoes--tied as tightly as possible. If I want to go out in "regular" shoes, I wrap my foot for several hours beforehand to shrink it enough to fit into a shoe. Within a few hours my foot is swelling inside that shoe to an uncomfortable level so my plans are usually dinner with friends and straight home.

One year after the lymphedema hit, I got married in a long gown and very comfortable shoes. My leg wrap peaked out a few times but it was my big day and I just had to let go of the embarrassment. A few weeks after our wedding, I was put in the hospital to, once again, try to do something with the lymphedema. It was the last hospitalization for lymphedema; nothing works and it never will.

It has now been over 11 years since my transplant and I've had a few issues, like fluid on the lung and acid reflux, that have caused some loss in lung function, but my numbers are still up there, just not in the clouds anymore. Last summer I had fundoplication surgery because of the acid reflux and I'm hoping it took care of it. Acid reflux can be a cause of rejection so I had no choice but to have the surgery. Recently I had hernia surgery due to a surgical site hernia which was much more painful than the fundoplication surgery! If something like that ever happens again, I'll learn to love the hernia.

I am now awaiting my husband's lung transplant. He also has Alpha-1 Antitrypsin Deficiency Disorder and his lung function is down to around 20%, low enough to qualify him for the waiting list. My mission is to not only stay healthy for myself but to make sure I'm able to see him through this whole process, and then to fulfill our dream of being a 'normal' married couple who can travel, walk on beaches, resume an active lifestyle, and count our blessings.

To end my story I must tell about my donor. In the hospital I had been told my donor was a 15-year-old girl killed in a car wreck. My mom had watched the helicopter land and noticed it came from the north. Two weeks after my surgery a news article, carried by the Associated Press, was featured in our local Sunday paper. My phone started ringing off the hook at 7:00am. There was the story, along with pictures, of a girl named Mandy killed on August 19 (my transplant was on the 20th), whose organs saved many lives. Her heart went to a teenage girl in Chicago and her lungs and liver stayed in Indiana. There was absolutely no doubt she was my donor but I followed protocol and exchanged letters with her mother, not revealing my name nor telling her I knew who she was. Less than a year after transplant I exchanged phone calls with her mother but her father couldn't bear meeting in person so, to this day, we've never met. I hope to change that someday.

*(Please see **Post-Transplant Story** continued on page 13)*

Support Groups & Events Calendar

AirWays posts coming events that are of interest to our readers. Please submit the name of the event, location, date(s), time(s), website link, contact person, and a short description of the event if needed. We are not able to include fundraisers.

Closing dates are the end of the months of January, March, May, July, September, and December. Due to printing and mailing schedules, please submit items for publication at least two weeks before the closing date.

Lung Transplant Support Groups.

Dover Campus, St. Clare's Health System

400 West Blackwell Street
Dover (Morris County), NJ
For information, call (732) 412-7330

St. Louis Second Wind Lung Transplant Association

Second Wind of St. Louis is now available on Facebook by searching that name.

Second Sunday of each month, 2pm, at Chris' Pancake and Dining.

Contact person: Amanda Helderle, 314-225-6751
may12usch@yahoo.com

Loyola University Medical Center

Third Tuesday every month, 7:00 PM
EMS Building Rm 3284, 2160 S. First Ave.
Maywood, IL 60153

Pre-, post-transplant patients, & support person(s)
Caregivers only support group, first Wednesday every month.
Combined Transplant Support Group, first Thursday every month. This meeting and Caregivers at same address.
For information, contact Susan Long (708) 216-5454,
slonng@lumc.edu

Emory Lung Transplant Support

First Monday of the month at 12 noon on the Emory Campus.
Location Changes. Contact Julia Bucksot at
jsbucksot@gmail.com for more information

Shands Hospital Lung Transplant Support Group

Shands Cancer Hospital, South Tower, 5th Floor
1515 SW Archer Rd., Gainesville, FL 32610
Contact: Micki Luck, nodurm@shands.ufl.edu
Phone: 352-519-7545

University of Texas Southwestern Transplant Support Group

St. Paule Auditorium, 5939 Harry Hines Blvd., Dallas, TX 75390. Pre-lung transplant patients and caregivers are also welcome.

Contact: Jodie C. Moore, MSN, RN, ACNP-BC
jodie.moore@utsouthwestern.edu Phone: 214-645-5505

WE REMEMBER



Mark H. Swartz
Warminster, PA

Member of Second Wind since 1998
Single Lung Transplant, May 9, 2000
University of Pennsylvania Medical Center
Date of Death: January 3, 2015



Roger Daily
Borden, IN

Double Lung Transplant, January 9, 2009
Duke University
Date of Death: November 29, 2014

*At the going down of the sun and in the morning
We shall remember them!*



Memories last a lifetime...

It is the memorable events that shape our lives. Birthdays, anniversaries, the arrival of a baby and the passing of a loved one are all occasions on which to remember someone special. A thoughtful way to remember that special event is by providing a donation to Second Wind in their honor or their memory.

In Memory Of Roger Daily

by

Mary K. Daily

Dennis & Kathy Lenfert

Julie Graham

Denise Johnson

Georgia Hedrick

Michael & Mary Temple

Francis & Helen Sample

Borden, IN High School

New Members and Membership Renewals November 2014 — January 2015

NEW MEMBERS

Maria Glasnapp	Patrick Haggerty
Sandra Patrick	Deborah Pratt
Dennis Rourke	Kale Willis
Annette Cook	

RENEWALS

Greg Briggs	Martine Cantier
David Courtney	Karen Ettinger
Lisa Fry	Robert Glim
Scott Larrimer	James Lyons
Douglas MacIntyre	Timothy Monahan
Michele OGuinn	Cheri Peirce
Lori Schilling	Alan Schwenck
Marilyn Sundt	Karen Swenson
Anita Tracey	Stacey Veasey
Craig White	

We also welcome all our new and renewed members who wish to remain anonymous.

(Events Calendar continued from page 12)

University of Chicago Medical Center

Lung Transplat Support Group for transpant recipients and those who are listed. Third Wednesday of every month, 5-6:30 pm.

Center for Care and Discoveru (CCD), 7th Floor Conf.Rm. 7710 5700 S. Drexel Ave., Chicago, IL 60637

Contact: Kaitlin Ray, LCSW

kaitlin.ray@uchospitals.edu or call 773-702-4608

Pager 6720

University of California San Francisco

Lung Transplant Support Group, Third Thursday of every month, 1-3 pm, Room 1015.

A505 Parnassus Ave., San Francisco, CA 94143

Contact: Avry Todd, MSW, 415 353-1098

Apryl.Todd@ucsfmedctr.org

St. John Medical Center

A Second Chance Lung Transplantation Support Group
26908 Detroit Rd. Second Floor Conference Room
Westlake, Oh 44145

Second Tuesday of most months 6-8pm

Group Discussion: Recipients, Caregivers, & Families

Contact Kathy Lewis (kathy2lungs@yahoo.com)

(Please see Events Calendar continued on page 14)

Donations to Second Wind Lung Transplant Association

The Board of Directors expresses appreciation to the following people for their financial support of Second Wind. Thank you very much for your donations, they are most appreciated!

General Fund

Garry Nichhols	Greg Briggs
Scott Larrimer	Juli Wilcox
Anita Tracey	Richard Kamm
Laura Labno	James Lyons
David McCourtney	

Donations for Financial Assistance Fund

Garry Nichols	Scott Larrimer
Tim Monahan	Chuck Schuele

Donations for Membership Fund*

Donald Gwinn	Garry Nichols
Karen Swenson	

* Membership Fund provides for waiver or reduction in membership dues for those with limited financial resources.

We also express our sincere thanks to all our donors who wish to remain anonymous.

CORPORATE DONATIONS

The Second Wind Board of Directors is delighted to start receiving corporate sponsorships to help support our mission and goals.

RAY BUICK, INC.

5011 W 63rd St, Chicago, IL 60638

has made a very generous donation to our Financial Assistance Fund. Thank you so much for your contribution from the Board of Second Wind and from our members who will benefit directly from your generosity.



(Post- Transplant Stoory continued from page 11)

I thank that family every single day for my life and the lives of my family and friends who were so affected by my illness.

I still marvel at the miracle of organ transplant.

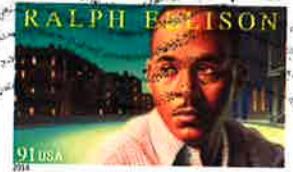


**Please Share This Issue
of AirWays With Friends,
Family & Colleagues**

Second Wind Lung Transplant Association, Inc.
1020 Gull Court
Palatine, IL 60067
RETURN SERVICE REQUESTED

EAM IL 601

24 MAR 2015 PM 11



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(Events Calendar continued from page 9)

Support Groups & Events Calendar

University of Washington Medical Center Seattle, WA
Meetings for 2015

Pre- and post-transplant Support Group

UWMC patients, their family and friends. Meetings are on the Second Tuesday of the month, 12:30-2:30.

Caregivers Support Group Meetings

Meetings on the 4th Wednesday 12:30pm to 2:00pm, January through October. Open to transplant families, friends, spouses & partners. No patients please. Both meetings are held in the Plaza Cafe Conference Rooms B/C.

Contact: Angela Wagner, MSW at 206-598-2676;
www.uwltsg.org

Second Chance for Breath Lung Support Group St. Lukes Medical Center

2900 West Oklahoma Ave., Milwaukee, WI 53201
For pre & post lung transplant patients
Contact Person: Ed Laskowski
laskowskiedward@att.net or call 414-231-3013

St. Joseph's Hospital & Medical Center

Lung Transplant Support Group
500 W. Thomas Rd.

Phoenix, AZ 85013

2nd Tuesday of every month, 11:45 am – 1:00pm

Mercy Conference Room

Contact: Kathy Lam, LCSW

Kathy.Lam@DignityHealth.org Phone: 602-406-7009

