SECOND WIND
LUNG TRANSPLANT ASSOCIATION, INC.

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

Donor Family Contacts: The Wisdom of Letters and Meeting

Jane Kurz, RN, PhD
Second Wind Board Member

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

After a family agrees to organ donation at the time of an individual's death, select organs are retrieved in the operating room and transplanted. About 2 weeks after the donation, the transplant coordinator sends a "thank you" letter to the family with very brief facts about the recipient. Graf in her book, "The Gift of Life" included a sample letter with these details: "The gift of your mother's right kidney was given to a 60 year old mother who lived in the metropolitan area. ... The gift of her left kidney was given to a 57 year old man with several children. His kidney failure was due to chronic high blood pressure. He no longer requires dialysis. Unfortunately, during our evaluation we found that your mother's lungs, heart and pancreas were not suitable for transplantation and therefore were not surgically recovered......" Some centers only will tell the recipient basic information about their donor, e.g., age, gender, and cause of death. Each U.S. center establishes guidelines for recipient-donor communication. The majority of centers will maintain confidentiality to protect the donor family and recipient. In Europe many countries have laws that prohibit the release of any information about donors or recipients to the other party, although transplant coordinators do give recipients the opportunity to write an anonymous "thank you" letter to the donor family (Dobbles, et al, 2009).

Typically, the organ recipient prepares a brief note to the family thanking them for their gift and generosity and acknowledging their loss. Most centers will provide guidelines for those who want to write a letter. (Couture in "The Lung Transplantation Handbook" available via the store at www.2ndwind.org provides excellent letter suggestions). The recipient gives the unsigned note to the center's transplant coordinator and the coordinator delivers it to the donor family. Neither party knows the identity of the other. Many patients have stated that it was important that they had an opportunity to express their gratitude and families have shared that these unsigned letters have provided them comfort. Most researchers report that contact by letter is preferred by both recipients and donor families as a first step. When donor families write, they often share information about their loved one's likes, dislikes, or physical characteristics

*(Please see **Contacts** continued on page 4)*

BOARD OF DIRECTORS

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.

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President's Notes

Cheryl A. Keeler, President

Second Wind Lung Transplant Association, Inc

Spring is finally here. The flowers are blooming and allergies are at a season high. Later in this Note I will address some of the concerns regarding Spring weather. First, the Board of Directors wants to bring you up-to-date on the activities of the Board and recent transplant news.

AirWays

I hope all of you enjoyed our 20th Anniversary Edition of ***AirWays***. It was quite an honor to assist Second Wind in accomplishing twenty (20) years of service to the transplant community. I want to express, on behalf of the Board of Directors, a special thank you to Karen Couture, Kathryn Flynn, and Paula Moscariello for sharing their personal transplant stories with all of us. Their years of post-transplant life give us all hope for a long and fulfilling post-transplant life. We also want to thank Mary Hardy and Ross Pope for the articles they wrote for the special Anniversary edition. If you are willing to share your story, please contact our Editor, at schumann10.ss@gmail.com or contact me at keelerc768@aol.com. Thank you.

Financial Assistance Program

In January and February of 2016, the Board has processed one financial assistance request from our members. A member needed financial assistance with a utility bill and we were able to pay $250.00 to his electric authority.

The ability to award grants to our members is directly related to the donations made by the membership and some corporate donations. All funds donated to the Financial Assistance Fund go directly to pay costs not normally covered by insurance, for our members who qualify for the Financial Assistance Program, which is based on financial need. If you need or want more information about the Financial Assistance Program, or if you want to make a donation to the Financial Assistance Fund, please go to our website: www.2ndwind.org and click on Financial Assistance Program.

Transplant News

American Lung Association (ALA)

Recently the ALA printed an article regarding the implications of weather on those of us with lung disease. According to the

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

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ALA whether it is summer or winter, rainy or windy, people with lung disease should pay attention to the weather report as sudden changes in the weather as well as extreme weather conditions can provoke lung problems.

Hot weather can be especially hard on people with respiratory disorders. Inhaling hot air is known to promote airway inflammation and exacerbate disorders like COPD. Since people with asthma already have inflamed airways, breathing in hot, humid air induces airway constriction in asthematics. Dry air can also irritate the airways of people with chronic lung disease. This can lead to wheezing, coughing and shortness of breath.

None of us can control the weather, but we can be proactive and prepared by keeping in mind the following tips:

- If it's cold outside, wrap a scarf around your nose and mouth to warm the air before it enters your lungs. Breathe in through your nose and out through your mouth.
- Access to air conditioning can be important during the hot summer months. Access it as often as you can.
- Monitor air quality forecasts. Air pollution can be very high both in winter and summer and can impact your breathing greatly.
- If the air is extremely dry, use a humidifier and monitor the air quality.

For those of us post-transplant, Spring weather can present a variety of hazards. A good friend of mine told me a story about Spring time I have never forgotten. He told me shortly after receiving a bi-lateral lung transplant he decided he felt so good he would take a ride in the countryside in a convertible with the top down and just really enjoy the Spring weather and the beautiful hills and fields. He spent a few hours just driving through the beautiful hills enjoying the sunshine and the scenery. Apparently the farmers were out in the fields turning the soil over getting their land ready to plant their crops. I'm certain that most of us have seen the large equipment out in the fields tilling the soil and preparing it for planting. It does look beautiful.

But, as the soil is turned over it releases mold spores into the air. My poor friend got a terrible lung infection from breathing in all of the spores that were released in the atmosphere by the farmers just doing their job. To this day, if I am driving or riding in a car with the windows down and I even see someone cutting their grass, let alone turning over the soil, I roll the window up immediately. If I know I'm going to drive through a rural area where planting is taking place, I just use the air conditioner and leave the windows closed.

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.

News: Medical Life Sciences & Medicine (www.news-medical.net)

An article was published on March 16, 2016 titled: "New Procedure Allows Kidney Transplants From Incompatible Donors." Many lung transplant recipients face kidney disease due to the medications we must take. Several of our long-term post lung transplant members have received a kidney transplant or are on a waiting list for a kidney transplant.

The article stated that researchers have found a way to stop patients from rejecting kidneys that have come from

*(Please see **President's Notes** continued on page 4)*

***(President's Notes** continued from page 3)*

incompatible donors, potentially slashing the waiting time for thousands of people in desperate need of the procedure. For the study, the researchers used a procedure known as desensitization which involves a "reboot" of the immune system that allows patients to accept kidneys they would otherwise reject. Significantly more patients who underwent the procedure were still alive after eight years than people who stayed on waiting lists or received a kidney from a donor who had died.

The method "has the potential to save many lives" says Dr. Jeffery Berns, kidney specialist and president of the National Kidney Foundation. It could also mean the difference between receiving a transplant and spending a lifetime on dialysis.

In the desensitization process, the patient's antibodies are filtered out of the blood. The patient then receives an infusion of other antibodies to ensure some protection, while the immune system sets about regenerating its own antibodies. For some reason that is not exactly known, the patient's newly produced antibodies are less likely to attack the transplanted kidney. Even if the patient's regenerated antibodies were a concern, drugs can be given to kill any white blood cells that may produce antibodies that would attack the organ.

As reported in the *New England Journal of Medicine*, Dr. Segev (Johns Hopkins University School of Medicine) and team compared patients who received a transplant from an incompatible donor with an equal number who stayed on waiting lists or received an organ from a compatible, but deceased donor. After eight years, 76.5% who had an incompatible donor were still alive, compared to 62.9% of those who stayed on waiting lists or received a kidney from a deceased donor and 43.9% who stayed on waiting lists without ever receiving a transplant.

We will follow this new procedure and report any additional information. What we want to find out is, if this procedure works for kidneys, can it also work for other organ transplantation? We don't know the answer to that question, but it is very encouraging for kidney transplant patients. Please have a wonderful Spring and stay healthy.

*(**Contacts** continued from Page 1)*

and they express hope that the recipient is feeling better (Finn, 2000).

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

The advantages to the donor family who made contact with the recipient were many. They reported: 1) a sense of satisfaction at learning the success of their donation, 2) feeling good at making personal contact with the other party, 3) feeling strengthened in the decision to donate, and 4) a sense that the late donor was living on in the recipient. Advantages to the recipient who met their donor family included: the ability to say "thank you" and closing the circle linking death to a new life, satisfying their curiosity to learn about their donor and the family who was willing to donate. In this study the disadvantages to both recipients and families were: 1) a sense of loss and guilt, 2) a sense of creating an emotional burden on the other party, and 3) expectations of the contact were not met. Some recipients felt pain at seeing their donor family grieving their loved one's death. Donor families reported a renewed sense of bereavement when they met. However, 79% of those who made the contact felt satisfied with the contact and 89% listed benefits to the contact. The study participants reported that the contact had its costs but almost all wanted to continue the contact.

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

When a family agrees to donate, they expect the donated organs to be used. Corr, Coolican and Moretti (2011), members of

*(Please see **Contacts** continued on page 8)*

2016 Donate Life Transplant Games

Cleveland, Ohio

June 2016

The Donate Life Transplant Games of America will be held in Cleveland, Ohio starting on Friday, June 10, 2016 with the Closing Ceremonies to be held on Wednesday, June 15. The aim of the biennial Transplant Games is to increase awareness for the life-altering benefits brought through the transplantation of organs, tissue and corneas. Organ transplants save thousands of lives each year and the Transplant Games celebrate the gift of life and honor donors and their families. The event also provides a platform for education on organ and tissue donation. Approximately 120,000 people in the United States are currently awaiting a life-saving organ transplant and donor registry lists in every state need continued growth.

Registration is now open for Competitors and Non-Competitors. The cost for a Competitor prior to April 30, is $160.00, and the cost for Non-Competitors is $35.00. The last day to register for the Games is May 20, and the cost between April 30 and May 20 is $180.00 and $40.00 respectively. There are numerous events approved for Medals. The 2016 list is:

- 5K/10K Run/Walk (open to the public)
- Lyrics for Life
- Basketball
- Table Tennis
- Golf
- Badminton
- Virtual Triathlon
- Ballroom Dancing
- Swimming
- Bowling
- Cycling
- Texas “Hold-em Poker
- Racquetball
- Bocce
- Tennis
- Volleyball
- Cornhole (Bean Bag Toss)
- Trivia Challenge
- Youth Olympiad
- Track & Field
- Darts

Besides the many competitive events, there will also be many special events including:

5K/10K Race Walk - This race/walk launches the Games by running or walking with thousands of participants in a downtown setting;

TGA Beach Party - Come enjoy lots of great food, games, music and more at the beautiful downtown Cleveland Edgewater Park;

Coffee House - An open mic/taping forum for donor families, living donors, recipients and professionals to share a few words. Participants can relax over coffee and dessert and share personal thoughts, stories, poems, songs and other creative expressions about how donation has affected their lives;

Donor Tribute Ceremony - This is a special tribute to our loved ones who have donated organs, tissue and corneas at the time of death and to living donors who have given organs so others could have a second chance at life. All donor families and Games participants are invited;

Transplant Workshops and Seminars - These sessions offer encouragement, education and support to those who have been affected by organ transplantation and/or donation;

Quilt Display/Quilt Pinning Ceremony - A large number of quilts will be displayed throughout the entire duration of the games. In addition, there will be a quilt pinning ceremony for those who wish to create a quilt square.

Quarter Century Club Dinner - An opportunity to all attendees to attend and celebrate recipients and donors of over 25 years. Open to all TGA attendees you are encouraged to attend this special event. Dinner and dance will be at the Cleveland Rock & Roll Hall of Fame and Museum.

Zumba Dance - Exercise in a fun environment with some raucous music among friends.

In addition to the above even.ts, many lung transplant support groups may plan gathering in Cleveland during the Games. As information becomes available regarding these special events, we will pass on the information on our web site and also on our Face book page: Fans of Second Wind Lung Transplant Association, Inc.

If you Google “2016 Transplant Games of America”, you will find the link for registration and also information on all of the events. Many of the Special Events are filling up fast, so I would encourage you to register early. We hope to see many of you in Cleveland this June.

When Facing a Lung Transplant, Failure Is Not an Option:

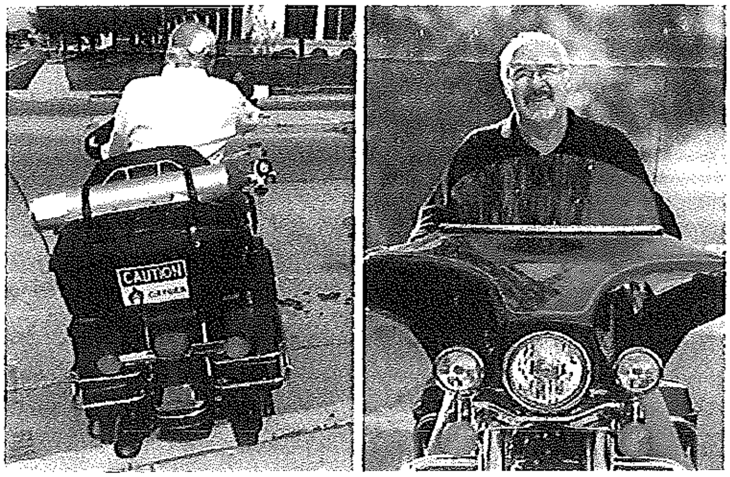
Marc Chelap's Story

(Thanks to the University of Chicago Lung Transplant Group for their kind permission to reprint this article.)

Before and after:

May 7, 2013 is the day Marc Chelap got his life back. "I consider it my birthday now," Chelap said about the day he had a double lung transplant at the University of Chicago. Most people would be scared going into a surgery like Chelap's, during which he would have each of his lungs removed, one at a time, and replaced with new, healthy lungs, but not him. He was ready. "Failure was never an option," he said.

Chelap was very sick before his transplant. He had emphysema, pulmonary hypertension, sleep apnea and atrial fibrillation. He was oxygen dependent, which meant he needed to carry an oxygen tank with him everywhere. His doctor suggested oxygen supplementation in 2006, but Chelap refused. However, in 2010, he was so breathless and weak that he felt he didn't have a choice anymore and agreed to get an oxygen tank.



Before and After

For three years before a double lung transplant, Marc Chelap took an oxygen tank with him everywhere, often strapping it to his motorcycle. Today, Chelap can breathe easy with his new lungs.

Chelap was first diagnosed with emphysema in 2006, but he'd been suffering from symptoms for about 12 years before his transplant. He used to hide his symptoms from friends and family so they wouldn't know how sick he was. His lung disease was so bad he would refuse to go anywhere he couldn't find a parking spot right next to the store because he couldn't make the walk, even with the oxygen. He had difficulty working, and he couldn't perform everyday tasks. Anytime he went to the store, even if he was only picking up one or two items, he would bring a cart to lean on, and if he needed to stop to catch his breath, he would pretend he was looking at something on the shelf. It was all to keep up appearances that he was okay. He would even hide his hands because his fingernails were blue from lack of oxygen.

Edward Garrity, MD

In 2011, Chelap's doctor recommended that he meet with the lung transplant team at the University' of Chicago to look into a transplant. He was feeling so bad by then that he knew he didn't have many options, so he agreed to go. When he first met with Edward Garrity, MD, Medical Director of the lung transplant program at the University of Chicago Medicine, Chelap learned he had a life expectancy of two years. That was a bit of a wake-up call because he had been telling himself that someday down the line, in maybe five to seven years, he'd look into getting a lung transplant. When Chelap learned that he didn't have anywhere near five years left if he didn't do something, he sprung into action. He started pulmonary rehabilitation right away. With a lung capacity that was less than 15 percent, there really was no other choice. He knew his chances of a successful transplant increased if he improved his strength and endurance.

Chelap's pulmonary rehabilitation consisted of education, exercise and a positive attitude. He went to a local hospital to work out three times a week, and he exercised every day at home. His goal was to log two hours on a stationary bike each day. In the beginning, it could take him five hours to complete those two hours because he had to take breaks if his oxygen levels got too low. Starting in 2011, he did pulmonary rehab for 14 months, and he lost 42 pounds, which helped him get in better shape.

Christopher Wigfield, MD

"Marc pushed himself so he'd be well enough for transplant," said Christopher Wigfield, MD, Surgical Director of the lung transplant program at the University of Chicago Medicine, who performed Chelap's transplant. "With his energy, independence and commitment to the process, he proved that if you go through this with the team and work with the doctors, you'll have a better outcome."

Wigfield said that by the time donor lungs were available, Chelap had only months, if not weeks, left to live. He praised Chelap for doing what it took to have a successful transplant. "He took care of destiny and amended his past behaviors. He had already quit smoking, but he also quit drinking alcohol,

*(Please see **Chelap** continued on Page 7)*

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and he was dedicated to his rehabilitation. The whole person has to be reconditioned prior to lung transplant, and Marc took a very active approach to that. His attitude was great. He followed the 'move it or lose it' motto and never stopped moving, which is difficult to do when you have such advanced lung disease."

Wigfield said Chelap is responsible for at least 50 percent of his success, but the collaboration between the entire team of doctors also made the good outcome possible. "This was a very complex case because Marc had co-morbidities, including pulmonary hypertension, that made transplantation more difficult," Wigfield said. "We were able to perform the transplant without using the heart-lung bypass machine, which is quite remarkable. That speaks to the health and quality of the new lungs received, the skill of the surgeons and the anesthesiologist, and the quality of the graft (how the lungs were attached to Chelap's body)."

Chelap 48 hours post-transplant.

When asked what was most remarkable about Chelap's surgery and recovery, Wigfield mentioned how well Chelap did before, during and after surgery. "It was a prime example of how good things can be when everyone works together," Wigfield said. He gives Chelap credit for having a positive, can-do attitude throughout the entire process.

Chelap has plenty of praise for the doctors and the University of Chicago Medicine, too. From the beginning, Chelap was Impressed by how the lung transplant team was accommodating and willing to coordinate his pulmonary rehabilitation at a hospital closer to his home near the border of Wisconsin. When it came to the surgery and recovery, Chelap was thrilled. He hardly felt any pain at all. "The most pain I felt after surgery was about a three on a one to 10 scale. I've had worse pain from dental procedures," Chelap remarked. He felt great after surgery, and was able to walk around the hospital during his stay. He remembers feeling like his old self soon after he woke up.

By the time the ventilator was removed the day after surgery, Chelap was talking like he always had been. "I called my sister and the nurses where I'd done my pulmonary rehab, and they were all in shock that I sounded so good. No one could believe that I had just gone through a double lung transplant," Chelap said.

Chelap didn't have any side effects from the medication, with the exception of a small tremor he felt for a little while when he was taking prednisone, a drug prescribed to prevent the body from rejecting tie transplanted lungs. He will have to take antirejection drugs for the rest of his life, but he tolerates them very well. He also said he doesn't really have any noticeable scarring, which he finds to be incredible.

Chelap also has high praise for his transplant coordinator Uma Bindingnavle. "She took care of everything and still does. I recently had an unrelated surgery to remove a tumor from my hand, and she made all of the calls and arrangements to make sure things got done. She's fantastic," he said. "And Dr. Garrity is my guy. He's been there through the whole process and recovery, and he's still there today. In fact, he was there every day while I was in the hospital recovering from my recent hand surgery, even on the weekends. The team approach is great. They all consult with one another to make sure their patients get the best."

Dr. Garrity has nothing but good things to say about Chelap. "For all the years I have been involved in transplantation, I have said that the right patient is as passionate about the transplant as I am. Marc is the right patient all the way."

Today, Chelap is 62 years old and feeling great. He walks 1.5 to 2 miles every day with his dog, typically in a nearby forest preserve. He has no problem doing many things that used to be a challenge for him. For example, he can now go to a store and park in the spot farthest from the door. Recently, he danced all night at a good friend's wedding.

When asked how he did it, Chelap said, "I gave myself a mental placebo every day, saying, "I'm going to live.' He never lost sight of that goal. His advice to other people awaiting transplant is to "treat this process like your life depends on it — because it does! Make sure you find good doctors and do whatever the doctors tell you to do. If you need to quit smoking, quit. If you need to stop drinking, stop. If you need to improve your diet and exercise, do it, even when it's hard — especially when it's hard. And then, on top of it all, remain positive."

Chelap and the physicians all agree that patients need to believe in themselves and adopt a mindset that failure is not an option. Attitude can go a long way toward helping you, both during the time you're waiting for transplant and during recovery from transplant. Marc Chelap is living proof that having a positive outlook and being dedicated to your own health can be a difference maker.

Advocate Christ Medical Center Lung Transplant Center

The Lung Transplant Program at Advocate Christ Medical Center in Oak Lawn, Illinois is a new and rapidly growing program that serves the Chicago metropolitan area including southeast Wisconsin and northwest Indiana.

Advocate Christ Medical Center is one of 12 acute care hospitals in the Advocate Health Care network that serves the greater Chicago area. Advocate is the largest health system in Illinois and is among the nation's top 5 large health systems based on quality by Truven Analytics. Advocate Christ Medical Center is one of four teaching hospitals in the network having affiliations with all major universities in the Chicago area. US News and World Report has ranked its Cardiothoracic Surgery and Pulmonology programs each within the top 50 in the nation.

As Advocate Health Care's organ transplant center, Advocate Christ Medical Center has the largest cardiac ventricular assist device program in the country that also feeds the large heart transplant program. The Lung Transplant Program received UNOS approval in 2013 and has been accepting patients for evaluation. The average waitlist time for our patients is about 40 days and many high acuity transplants have been performed with excellent outcomes.

Although a new program, its surgical and medical directors have many decades of combined experience and have been directors at other major academic centers. All of our staff come with experience from other large transplant programs. The Cardiothoracic ICU currently has 37 beds and will expand to a total of 56 beds in January 2016. The new Outpatient Pavilion accommodates the Lung Transplant offices, clinic, pulmonary rehabilitation and an on-site pharmacy. Other specialists in the program include a dedicated transplant nephrologist, infectious disease specialist, psychologist and clinical pharmacist.

The Lung Transplant Program operates closely with the Health System's Pulmonary Hypertension Center and Adult Cystic Fibrosis Program. The staff in our program is always available and is accepting patients with end-stage lung disease for transplant evaluation from across the country.

Dr. Charles G. Alex MD is the Medical Director and Transplant Pulmonogist for the program. Dr. Alex formerly held positions at Loyola University Medical Center as the Medical Director of the Lung and Heart-Lung Transplant program, and Edward Hines, Jr., VA Medical Center as Director of the Division of Pulmonary and Critical Care Medicine.

(Second Wind recognizes submission of this article to Advocate Christ Medical Center.)

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*(**Contacts** continued from Page 4)*

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

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

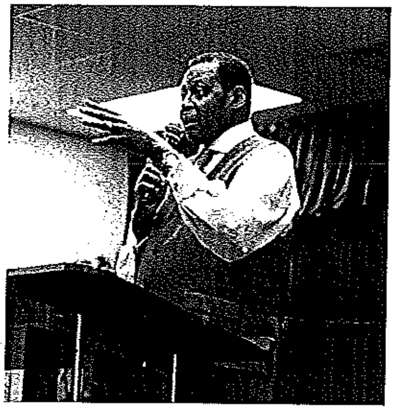
*(Please see **Contacts** continued on page 9)*

Pastor Returning to Pulpit Today

After Life-Saving Double-Lung Transplant

In what is certain to be an emotional church service, prominent Chicago minister Rev. Joseph Kyles is returning to his pulpit today for the first time since undergoing a life-saving double-lung transplant at Loyola University Medical Center. The media were invited to cover the Easter service 11 a.m. March 27 at Promise Church of Chicago, 4821 W. Chicago Ave.

For two years, a debilitating lung disease that caused severe shortness of breath robbed Rev. Kyles of the ability to give his high-energy sermons at Promise Church of Chicago, which he founded with his wife, Chrystal.



"I'm greatly looking forward to preaching again," Rev. Kyles said. "I had not been my normal, animated self since March of 2014. I need energy to speak. It's our tradition and history." Rev. Kyles expects the service will be very emotional. "People are going to be glad to see their pastor back in the pulpit," he said.

Rev. Kyles, 54, said he had enjoyed excellent health until he was diagnosed with pulmonary fibrosis, a progressive lung disease that causes lung tissue to become thick, stiff and scarred. As the disease progresses, it becomes increasingly difficult to breathe. Even though he was breathing supplemental oxygen, Rev. Kyles was unable to exert himself without gasping for breath. Some days, he could barely get out of bed in the morning.

"Rev. Kyles has a tremendous spirit," said Loyola pulmonologist James Gagermeier, MD. "He has a perspective that enabled him to persevere despite more than a few setbacks."

Today, with every breath he takes, Rev. Kyles experiences the dramatic difference the transplant has made. "I can sense that I have a new set of lungs that are not damaged," he said. "I feel great." Rev. Kyles noted that the theme of his church is God's unbroken favor. "I preach that you will see a continual stream of God's favor in your life," he said. "That certainly has happened to me this year."

Rev. Kyles said he is extremely grateful to his donor and to the doctors, nurses and everyone else who made his transplant possible. "I feel like I owe a big debt," he said. "I will use my life to express my thanks."

Loyola thoracic surgeon Wickii Vigneswaran, MD, performed Rev. Kyles' double lung transplant on Feb. 6, 2016. Rather than cutting through the breastbone, Dr. Vigneswaran made two smaller incisions on the side of Rev. Kyles' chest. This less-invasive procedure enabled a faster recovery, said Dr. Vigneswaran, who has performed more than 500 lung transplants.

Loyola has performed more than 800 lung transplants, by far the most of any center in Illinois. Last year, Loyola performed more lung transplants than the three other Illinois lung transplant programs combined. In May, 2014, Loyola became the only center in Illinois to perform five successful lung transplants in just over 24 hours.

CONTACT:
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Media Relations
Loyola University Health System
(708) 216-2445 (Office)
(708) 441-7728 (Cell)
jritter@lumc.edu

(Second Wind gratefully acknowledges rhe permission granted by LUMC to reprint this press release, as well as Jim Ritter's providing the article for AirWays.)

*(**Contacts continued from Page** 8)*

to meet the donor family because they feel they do not have the emotional strength to include them in their complicated life.

There are no wrong decisions with regard to contact. One Second Wind member shared that she writes yearly to her donor family and has never heard from them. She stated, "I've talked to a lot of donor families and they are glad to get the letters but they cannot handle the idea of meeting or corresponding with the recipients. And I think that's perfectly normal." (Finn, 2000). One might also find that they write a first letter and do not get a response for several years. This might reflect the time when the donor family is adapting to their loss and grief. Another Second Wind member reported that he talked often to his donor family by telephone for several years and eventually attended the wedding of his donor's sister with positive responses from all. These are all variations of "normal".

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

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

Cincinnati Support Group
Second Thursday of each month at 6:30pm, hosted at the home of Robert and Cynthia Lohstroh; 4120 Beamer Ct., Cincinnati, OH 45246. Phone: (513) 752-0451.
Covers Cincinnati, Dayton, and Nothern Kentucky.

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 Helderie, 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

Transplant Anniversaries

JANUARY 2016

Name	Transplant Date	Yrs
Paula Moscariello	**1/1/1994**	**22**
Dennis Wright	1/9/2012	4
Karen Jacobsen	1/16/2007	9
Michael Thomas	1/16/2012	4
Robert Klein	1/17/2010	6
Karen Couture	**1/21/1996**	**20**

FEBRUARY 2016

Name	Transplant Date	Yrs
Maria Loss	2/1/2008	8
Karen Ettinger	2/1/2012	4
Sandra M. Andersen	**2/3/2001**	**15**
Cheryl Keeler	**2/3/2005**	**11**
Ross Pope	2/10/2014	2
Everett Johnson	**2/14/2006**	**10**
Martha C. Becker	**2/16/2004**	**12**
Peg Matthews	2/16/2010	6
Bernadette Boyer	2/25/2014	2

Congratulations to all who celebrate another milestone!

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)

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

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

(Please see **Events Calendar** *continued on page 12)*

NEW MEMBERS AND MEMBERSHIP RENEWALS
JANUARY 2016 — FEBRUARY 2016

NEW MEMBERS

Daniel Cupp
Sheryl Helt
Katie Moyer
Justin Stewart
Kathryn Bryan
Lydia Burton

NEW CORPORATE MEMBER

Advocate Christ Medical Center
c/o Dr. Charles Alex

MEMBERSHIP RENEWALS

Carolyn Blaylock
Diane Desiderio
Karen Effinger
Kevin Gargan
Robert Glim
Dave Griggs
Gwen Herron
Rick Kamm
Kathy Lewis
Peg Matthews
Jackie Moody
Tina Orlita
Ross Pope
Brian Pulasky
Susan Sweeney
Michael Thomas
Dennis Wright

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

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Help Wanted!

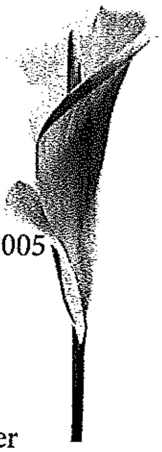
Have you ever wondered what it would be like to live in the fast lane of high energy newsletter publishing? Well, opportunity just knocked. Your faithful editor is ready to move into the far right lane and give someone else a chance. No experience is necessary, but wouldn't hurt, especially with Adobe InDesign.. Training will be made available, and non-members would be welcome, so if you have a spouse or acquaintance who would consider this we would also consider that. I would like to surrender my office when possible. If there are any wannabee editors out there, please contact Steve Schumann (schumann10.ss@gmail.com) or Cheryl Keeler (keelerc768@aol.com) to talk it over. As you've probably already figured out this is a voluntary position and no one is breaking down my front door yet, so its not too late to jump in.

WE REMEMBER

Darcy Shaw
DeForest WI
Date or Birth: 1-7-1951
Bilateral Lung Transplant 3-23-2005
U of Wisconsin Hospital
Date of Death: 10-16-2015

Stacy Vessey
Spicewoof, TX
Date of Birth: 4-12-1963
Bilateral Lung Transplant 3-14-2005
Date of Death: 12-25-2015

Deborah Pratt
Salisbury VT
Duke University Medical Center
Transplant Status Unknown
Date of Death: 2015



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

\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ ////////////////////////////////

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

Diane D. Desiderio
Dave Griggs
Michael E. Thomas

Donations for Financial Assistance Fund

John Jordan

Donations for Membership Fund*

John Jordan
Peg Matthews

* 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.

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

[redacted]

19810-326010

(Events Calendar continued from page 13)

Support Groups & Events Calendar

University of Washington Medical Center Seattle, WA Meetings for 2016 (schedule pending).

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

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. 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

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 Discovery (CCD), 7th Floor Conf.Rm. 7710
5700 S. Drexel Ave., Chicago, IL 60637
Contact: Fran Hammon, LCSW
frances.hammon@uchospitals.edu or call 773-702-4608
Pager 6720