

Vol. 26 - No. 6 May 2017 - July 2017

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HIKE FOR LUNG HEALTH

Second Wind and the Respiratory Health Association will take part in the 2017 Hike for Lung Health on Sunday, September 17, 2017. 10:00 a.m. start time at Lincoln Park, Chicago.

Registration is now open for the annual Hike for Lung Health sponsored by the Respiratory Health Association, Chicago, Illinois as the Host Charity and by Second Wind Lung Transplant Association, Inc. as a Charity Partner.

On Sunday **September 17, 2017** walkers will gather and walk a one mile or a three mile path through Lincoln Park, Chicago, Illinois to raise awareness about lung disease and to raise funds for lung disease research and education. The **Second Wind Team** will walk to raise funds for their Financial Assistance Program which provides funds to members for expenses associated with lung transplantation that aren't covered by insurance, such as, co-pays for medication, costs of temporary lodging, and costs of medical equipment that aren't covered by insurance.



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:

keelerc768@aol.com

Thank you!
The Editor



And They're Off!

and set challenges and goals for PR participants.

Many groups can form across the country to walk for **Team Second Wind**. All money raised by Second Wind Team Members goes 25% to lung disease research and education and 75% to Second Wind's Financial Assistance Program. Registration is \$15 and you receive a Hike T-Shirt in the mail if you are a Virtual Walker.

You do not need to be present to participate in this worthwhile event. You can join **Team Second Wind** as a Virtual Walker and walk in your own hometown. Many pulmonary rehab groups are joining as Virtual Walkers and are tracking their distance during Pulmonary Rehab sessions. This is a great way to motivate



And More Enthusiastic
Participants!

(Please see **Hike** continued on page 3)

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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:

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Send hardcopy submissions to the editor:

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President's Notes

Cheryl A. Keeler

Second Wind Lung Transplant Association, Inc.

The Board of Second Wind hopes all of you are enjoying the Summer months and that none of you looked at the eclipse without the proper eye ware. We want to bring you up-to-date on the activities of the last few months and share some information of some upcoming events.



AirWays

This edition of the newsletter covers the months of May, June and July. AirWays is one of the major methods Second Wind utilizes to fulfill its' Mission to improve the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concerns and their families,

caregivers and loved ones by providing support, advocacy, education, information and guidance. We strive to provide education and information by the articles we publish here in our newsletter. Your help is needed to fulfill this effort. We would like to publish more articles about personal transplant journeys. Your individual stories give hope and information to those still awaiting a lung transplant. If you are willing to tell your transplant experience, please write your story and email a copy, along with your picture, to me at keelerc768@aol.com.

As many of you are aware, Second Wind and the lung transplant community lost a great friend and follow Board Member on August 17, 2017 when Steve Schumann passed away. Please read the article *The Loss of a Friend* that appears later in this newsletter. Words can't express the sadness and loss the Board feels. Steve was an integral part in the publishing and delivering AirWays to you and the numerous transplant centers across the country for many years.

Financial Assistance Program

Since the last edition of *AirWays* five (5) requests for financial assistance. These requests consisted of the following: one request for help with transportation - \$267.73; one requests for help with a donut hole for medication - \$1,000. – one request for help purchasing a Spirometer - \$330.37; and two requests for help with temporary lodging - \$1,738.48; for a total amount granted of \$3,336.58. Thank you to all who made donations to the Financial Assistance Fund.

So far in 2017, Second Wind has received a total of eighteen (18) requests for financial assistance. This program is funded solely by your donations to the fund and any fund-raising

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

(Hike continued from page 1)

To register, go to www.hikeforlunghealth.org, and click on Register. You will be asked if you want to join an existing team – **Yes – Join Team Second Wind.**



Midas, the Wonder Dog,
Second Wind's shortest but most
enthusiastic Hiker!

Team Second Wind. To make a donation, go to www.hikeforlunghealth.org and click on the Donate button, then click on Search/Sponsor a Participant, then click on Team Search and click on **Second Wind Team**. You will find the "Donate Now" button on the right hand side of the page. This is a great way to give back to the transplant community that has done so much for all of us who are lung transplant patients, either pre-transplant or post-transplant.

Please get out there and support Team Second Wind.

Book Sale

The following books are available for sale from Second Wind's Store. These books are great books for anyone considering a lung transplant or if you are already transplanted. Shipping costs are included for shipment. Second Wind accepts all major credit cards and/or PayPal. Payment can also be made by check. Please go to our web site: www.2ndwind.org Click on the Transplantation button and you will find the Second Wind Store under that tab.

The Lung Transplantation Handbook (Second Edition): A Guide for Patients

This comprehensive, 270-page book, written by lung transplant recipient and Second Wind member Karen A. Couture, covers the entire transplantation process from beginning to end for both lung and heart/lung transplants.

Price: \$36.00 (Includes postage)

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An Exercise Program for Individuals with Lung Disease: Rationale and Programming.

An excellent manual written by Dr. William F. Brechue with programs designed for those with lung disease. It has 70 pages and includes: Flexibility Program, Resistance Exercise Program, Machine Program,, Dumbbell, Calisthenics Program, Aerobic Exercise Program.

Price \$20.50 (Postage included)

If you have any questions, please contact Cheryl Keeler at keelerc768@aol.com.

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.

efforts taken by Second Wind and its members. Earlier in this edition, we informed you about the Hike for Lung Health that is taking place on September 17, 2017. Second Wind is a Charity Partner with the Respiratory Health Association who is the Host Charity. **This event is Second Wind's only fundraising event for the year.** Seventy-five percent (75%) of the money raised by Second Wind will go directly into your Financial Assistance Fund. The other 25% goes to RHA for lung disease research and education.

Second Wind has no employees. We operate by the efforts of our eight- member volunteer Board. If you can't attend this event, we are asking that you please consider making a donation in support of your Second Wind Team. To make a donation please go to: www.hikeforlunghealth.org, click on the donate button, then click on Search/Sponsor a Participant; then click on Team Search and click on Second Wind. From there you can make a donation in support of the Second Wind Team. This is a great way to give back to the transplant community! If you have any questions, contact Cheryl Keeler, President of Second Wind at keelerc768@aol.com. Thank you.

Transplant News

American Society of Transplantation

The AST has worked to provide an educational and friendly forum for all transplant professionals to advance the field of transplantation and improve patient care. As a new initiative for this year, AST has announced their leadership will directly work with patients and live donors by hosting the 2017 Transplant Patient Summit, which will take place at the Mayflower Hotel on October 23-24, 2017 in Washington, D.C. The goal of the conference is to invite two transplant recipients, or donors, from each state to help them become transplant ambassadors and empower them to advocate for the field of transplantation from both a legislative/regulatory and fundraising capacity. The AST will provide a stipend for travel costs and will cover each attendee or live donor's hotel stay. Patient representatives have already been selected from each state. We await the outcome of the conference and look forward to a report from AST on the success of this conference.

American Lung Association

On May 22, 2017 the National Heart, Lung and Blood Institute announced the first ever COPD National Action Plan. The ALA served as a lead partner on the Action Plan. The plan was shared at the American Thoracic Society annual conference in Washington D.C. Key goals of the plan include the call for greater public awareness of COPD risk factors, improved

quality of care and increased research efforts surrounding chronic obstructive pulmonary disease (COPD).

A multipronged and comprehensive approach is needed where healthcare providers, patient advocacy groups and federal agency partners all play a role to adequately address COPD – a leading cause of death and disability in our nation. More than 11 million Americans are living with COPD and it is the third leading cause of death in the United States. There are a variety of risk factors leading to COPD, including smoking, air pollution, secondhand smoke, dust, fumes and chemicals. To address prevention of COPD, the plan focuses on risk factors and calls for increased access to tobacco cessation services, prevention strategies to limit exposure to tobacco, and objectives that include increased disease tracking to help improve COPD prevention and management. The ALA strongly supports the strategies put forth in the new COPD National Action Plan which will not only save lives but also improve the quality of life for those living with COPD.

United Network of Organ Sharing (UNOS)

UNOS celebrated its thirty-five (35) year anniversary in July 2017. Since 1982 the UNOS Organ Center has been working to help organ procurement organizations and transplant hospitals make transplants happen. The Organ Center's history actually predates UNOS as an organization. It was founded by the Southeastern Organ Procurement Foundation as the Kidney Center. Initial funding came through a grant from the American Kidney Fund.

When UNOS was incorporated in 1984, the Organ Center became one of its most fundamental services. Over time, its role has grown to include four primary responsibilities:

1. Placing organs for transplantation
2. Arranging transportation for organs
3. Maintaining the national transplant waiting list
4. Providing informational and logistical support to the U.S. transplant community

One of the most unexpected and horrifying challenges faced by the Organ Center occurred on September 11, 2001. The tragic events of that day required that all air craft were grounded. There were planes with organs on board coming down everywhere across the country without recipients lined up where they were landing. The OC employees were scrambling, running import matches, calling transplant centers, talking with courier services just trying to make sure that even though nothing was where it was supposed to be, nothing more would be lost. Due to the efforts of transplant professionals nationwide, including the vital support of Organ Center staff, no candidate deaths are known to have occurred as a direct

(Please see President's Note continued on page 8)

The Loss of a Friend

During the early morning hours of August 17, 2017 Second Wind Lung Transplant Association, Inc., and the entire lung transplant community lost a very dear friend as Board Member Steven C. Schumann passed away.



Steve was a very accomplished individual. He earned his Bachelor of Science in pharmacy from the University of Illinois at Chicago and was a Registered Pharmacist. Most of his working life was spent in the pharmaceutical field. Steve worked as the Director of Pharmaceutical Technology for Pfizer Pharmaceutical Company as well as Searle Pharmaceuticals

Inc. and Watson Pharmaceuticals, Inc.

In August 2003 Steve was diagnosed with idiopathic pulmonary fibrosis and in May 2005 he was listed for a lung transplant. On July 21, 2007 Steve received a left lung transplant at Loyola University Medical Center.

In early 2009 Steve joined Second Wind and later that year he became a Board Member and an officer of the Board. He was the First Vice President of the Board and volunteered to be the Editor of *AirWays*. Steve told the Board that his motivation for joining the Board was simply to find another way to balance the free gift he had received. He said "There is no individual to whom I am able to repay this debt, but it is within my power to work to promote the mission and goals of Second Wind. Since my transplant I have also done my part to promote Gifts of Hope, Respiratory Health Association of Metropolitan Chicago, and Pulmonary Fibrosis Coalition. I have done this through personal speaking engagements, fund raising activities, and personal contributions. As I approach retirement, I plan to continue to volunteer my time to promote awareness and support for these causes."

Promote and volunteer he did! There are no words to describe what Steve accomplished for Second Wind and his contributions are too numerous to mention all of them in this short article. However, some of Steve's contributions need to be celebrated.

Steve, by himself, put together and got published our newsletter *AirWays*. From 2009 until April of this year, Steve was our Editor. He spent hours putting the newsletter together and making sure that each newsletter contained the most up-

to-date information on lung transplantation. He took care of the mailing of the newsletter to all of Second Wind's membership and to 75 lung transplant hospitals across the country. Steve's family has told me he thought of *AirWays* as "his baby" and it really showed. The job of Editor consumed much of Steve's time to keep the newsletter going, and for that Second Wind is forever grateful to Steve and his family for allowing him to devote such time and effort for the transplant community.

Steve not only volunteered to be a Board officer and the Editor of our newsletter, he also volunteered to be a Mentor through our Peer Support program mentoring new transplant patients by sharing his own experience, strength and hope. He also shared his transplant journey with patients at the Loyola University Medical Center support group meetings.

Steve loved his second chance at life and wanted to live every moment to its fullest and to give back to the transplant community for the gift he had received. Through his actions and commitments, Steve repaid that debt. One of my favorite pictures of Steve is him on a zip line in Alaska, just having the time of his life on vacation with his family.



One of my Board Members said he hoped the Angels came down to greet Steve on August 17th. I believe in my heart that the Angels did come down to greet Steve and they took him home to be with our Lord.

Steve is survived by his former wife, Charlene Schumann; his daughter, Rebecca (Robert) Casarez of South Bend; son, Scott Schumann of Mt.

Pleasant, MI; and his two-year old granddaughter Clara, that he loved more than life itself. Steve was a good, kind and loving man. His generosity and friendship, to me personally, and to the Board of Second Wind and the entire lung transplant community was great. Those of us who knew him personally are much better off as a result of our friendship. Rest in peace in God's blessings my dear friend. Your work is done.

Cheryl A. Keeler
President, Second Wind

“The Way I Walk: From Tugboat to Transplant”

by Cathy Cuenin

A book review by Jane Kurz, Ph.D., R.N.
Second Wind Lung Transplant Association, Inc.

Do you know someone who has lymphangioleiomyomatosis (LAM) and never could understand exactly how it differed from all other lung problems? Do you ever wonder if registered nurses have an easier time in this transplant journey than non-health related folks? Are you a person who just likes a good transplant story? If you answered “yes” to any of these questions, then you should read this book. It is only 129 pages but it is packed with much information without being boring.

Cathy Cuenin starts her story when she married her true love at age 24 years. After graduation she accepted her first registered nurse job in Juneau, Alaska, where she and Loren made their home for many decades. She weaves her tale around her husband’s tugboat work, the relationship with her sister (Mary), family visits, birth of her son (AD), her work, and many emergency department visits.

Rather than provide many dry facts she tells her story with humor about the first time she needed a chest tube. The cause of her collapsed lung was not known but many physicians tried various explanations, e.g., too much running. Her experiences with the chest tubes (insertions, drainage, and removal) vary from good to not-so-good to reflect the skill levels of the health care team. This is where one can see that the nurse might know what should be done but making it happen in a timely manner is another issue.

The reader will also appreciate the beauty of Alaska that might keep a person “in this wilderness”. The weather can be cold and rainy for days, communities are small, and health-care resources are sparse. However, Seward’s Folly, as Cathy calls Alaska, includes stunning mountains, breathtaking scenery of vast land and glaciers, amazing sea lions, moose, bears, and whales. A trip to the Emergency Department (ED) is not like that in the urban cities. It is faster to drive in one’s own vehicle or travel by plane than to call an ambulance.

Cathy used the simile of “riding the waves” so the reader understands the challenges associated with LAM for her and her support system, i.e., Loren, her mother, her sister, and friends, and even her cats. Her chapters alternate from “Then” and “Now”. The “Then” chapters give the readers a glimpse into her life on the tugboat, raising her son, living with Loren, working, and facing normal problems along with exciting adventures of Alaskan life.

The “Now” chapters focused on the symptoms, the transplant, and the other health issues. In the second chapter she related her first chest tube insertion. Readers will appreciate her fears and the ED repeat visit, and health professionals will find the use of

a “knitting needle” interesting. In Chapter four she shares her tale about how she managed when she was first diagnosed. The description of LAM was easy to understand with just a taste of a few statistics. In Chapter six Cathy presented information about her pleurodesis, a roughening of the pleura, and the LAM Foundation. In Chapter 8 she described life in the hospital with chest tubes and her eventual move to her parent’s home in California. In Chapter 10 she disclosed how she worked diligently to become stronger using acupuncture, aromatherapy, meditation, and yoga and how her lung collapsed (again!) as she was leaving for her son’s college graduation.

It was at this time that Loren attended a LAM conference where transplantation was presented as a treatment option. He was the one who encouraged Cathy to pursue being listed. Following chapters described her moving to California to wait for the transplant, leaving the workforce, and getting the call. The specific details might differ for other transplant recipients but the tension of waiting and the excitement of the call are the same.

Those who have been transplanted will find her stories of her hospital recovery fascinating and funny. Health care professionals will have comments about the physician’s placebo use of oxygen. (It was effective!) One’s vocation has an effect on developing us into the people that we are. Cathy spends a chapter talking about her various nursing roles when she worked with the elderly, in the obstetrical unit, as a school nurse, as a hospice nurse in the homes, and as a community health nurse working with people from the Tlingit tribe. Her stories give the reader insight in her view of life and death. The chapter on infection control interventions will resonant with many and the book could have ended here. However, her challenges continued as they do for many transplant recipients.

Cathy developed a skin cancer that spread to her lymph nodes and then metastasized to other areas in her body. She shared her surgical treatment with skin grafts, chemotherapy, and radiation. It does not matter that the reader does not know what type of cancer was present. Others experiencing a similar issue will gain from hearing how she adjusted with caps, scarfs and close friends. Her coping included reframing her view of herself. Her identity was tied to herself as a nurse, healthy person, and an athlete but it had to change to her seeing herself as “what is”. The last chapter ends on a happy note as she is recovering from radiation and has regained her energy, appetite, and general health. She closes with appreciation to many.

The chapters are very short so it is possible to finish it in one afternoon. However, the reading is so relaxed that it is easy to miss the important points. When I finished the book, I had to re-read it because I missed several important details, e.g., how she coped during the waiting period. A minor criticism is that there are no dates so the reader does not have a time perspective. It was only after I carefully re-read the chapters that I concluded that she waited 3 years for her transplant. The last page of the book includes a one paragraph description of the LAM Foundation and the Second Wind Lung Transplant Association with electronic links. If you want to purchase this book, you can find it at amazon.com for \$10.95.

Mohs Micrographic Surgery: A Treatment Option for Skin Cancer

Dr. Juliana Gao and Dr. Diana Bolotin

University of Chicago Medicine, Section of Dermatology



It is well established that transplant recipients have a higher risk of developing skin cancer, likely due to a combination of immunosuppressive medications to prevent organ rejection, skin type and other risk factors such as history of sun exposure. It has been estimated that solid organ transplant patient are 65 times more likely to develop squamous cell carcinoma, and 15 times more likely to develop basal cell carcinoma than the general population. The actual risk for each patient depends on the dosage and duration of their immunosuppression, specific types of immunosuppression used and the cumulative amount of sun exposure over one's lifetime. In this issue, we will

discuss the use of Mohs micrographic surgery for treatment of squamous and basal cell carcinoma.

Why Mohs micrographic surgery?

Mohs micrographic surgery (MMS) was developed by Dr Frederic Mohs in 1933 at the University of Wisconsin. However, it did not become widely used until the 1970s and 80s after the technique was modified by Dr Perry Robins at New York University. Although the original technique of applying chemical paste directly onto patient's skin is no longer used, the modified method of examining the tissue with frozen histology sections is still utilized today in every Mohs surgery laboratory. MMS is performed by dermatologic surgeons who are specially trained in excision by MMS method, examination of MMS specimens under the microscope, and repairs of the defects after surgery.

MMS is different from a standard excisional surgery. Standard excisional surgery involves cutting out a standard wide margin around the cancer site, sending the specimen to a separate laboratory for processing and evaluation of margins which can take up to 10 business days to be resulted, and repairing the site before that result is known. MMS is performed in multiple stages, with each stage taking a small margin of normal skin and examining the tissue under the microscope each time until a clear margin is confirmed and then closing the resulting wound.

Standard excision uses routine histology processing to look at

specimens, which examines the entire specimen as snapshots of the margin at preset intervals. MMS uses a special orientation and processing technique for tissue such that 100% of the margin of tissue is examined with each stage prior to closing the wound. Thus, the major advantages of MMS are: (1) excellent cure rates with the cure rate for squamous cell and basal cell carcinoma approaching 98-99% for most common lesions (2) ability to spare the most amount of normal skin by taking small margin stages and (3) knowing the result of margin analysis before repairing the wound.

What to Expect During the MMS Procedure

A typical Mohs micrographic surgery starts with cleaning the surgical area with a disinfecting cleanser such as chlorohexidine, alcohol or iodine. Since patients remain completely awake during the entirety of the procedure, local anesthetics such as 1 to 2% lidocaine are injected in a circle around the skin cancer to numb the area. The local anesthetics work very fast, with peak onset within 1-2 minutes after injections and last for several hours.

After ensuring the treated area is completely anesthetized, the Mohs surgeon will often first use a curette to scrape away any visible portion of the skin cancer. Tumor cells feel very different from normal skin under the curette, therefore scraping also allows the surgeon to estimate the size and extent of the tumor. After this, the surgeon then uses a scalpel to remove a thin layer of skin with a small (1-2mm) rim of normal looking skin around the skin cancer site.

The removed tissue is a disc, and is flattened and oriented on a gauze pad to preserve the tissue orientation when looking at the tissue on a slide under the microscope. Then the tissues is taken to the Mohs laboratory to be processed. This is what is known as "taking a stage" and after this, the patient is bandaged and can rest in the waiting room.

In the lab, the specialized Mohs technician marks the orientation of the tissue on a Mohs map and this map is where the surgeon marks what is seen under the microscope. The technician then works to process the tissue, place it on glass slides and stain it for examination by the Mohs surgeon. It takes about one to two hours to process the specimen, depending on the laboratory set up. During this time, the patient can eat and drink, rest, read or walk around.

After the tissue is processed and slides are prepared, the surgeon can examine the tissue under the microscope. If there are any cancer cells present, the surgeon marks the location on the oriented Mohs map and the patient is brought back to the surgical room. The Mohs surgeon will then remove another thin layer of tissue only from the corresponding location that still has tumor. The process is repeated until the removed tissues are cancer free.

(Please see Mohs continued on page 9)

Transplant Anniversaries

MAY 2017

Name	Transplant Date	Yrs
Marc Chelap	05-07-13	4
Maggi Czoty	05-02-13	4
Mary Loretta Gallagher	05-08-13	4
Mary Hardy	05-31-02	15
Scott Larrimer	05-29-10	7
Timothy Monahan	05-14-13	4
Doug Powers	05-31-99	18
Lori Schilling	05-09-03	14
Carla Schworer	05-31-14	3
E. Samone Streetman	05-17-16	1
Samuel Tambyraja	05-14-16	1
Robert Tharp	05-31-16	1
Michael L. Thomas	05-18-16	1
Craig White	05-25-10	7
David Yennior	05-02-09	8

JUNE 2017

Name	Transplant Date	Yrs
Bill Berkson	06-19-04	13
Dennis Boyle	06-12-16	1
Brian Conley	06-05-15	2
Diane Desiderio	06-11-01	16
Katherine Glasgow	06-04-97	20
Rhonda Lyman	06-11-15	2
Michael Olson	06-04-14	3
David Pick	06-28-11	6
Jim Powers	06-23-09	8
Linda Watson	06-07-11	6
Paul Woods	06-10-13	4

JULY 2017

Name	Transplant Date	Yrs
Cecil Carter	07-21-13	4
John Curtin	07-20-07	10
Chuck Freiburger	07-08-14	3
Kathy Lewis	07-02-04	13
Robert Lohstroh	07-20-09	8
Cathy McGill	07-13-85	32
Nancy O'Mara	07-26-16	1
Frank Shields	07-16-12	5
Anita Tracey	07-03-05	12
Gail Weadon	07-17-15	2

(President's Notes continued from page 4)

result of the flight ban.

All of us in the transplant community owe a great deal to the efforts of the Organ Center and its professional staff.

Have a healthy and happy Summer and enjoy the Labor Day Holiday!

WE REMEMBER

Steven C. Schumann
Palatine, IL

Date of Birth: 10-08-1947
Single Lung Transplant 07-21-2007
Loyola University Medical Center
Date of Death: 08-17-17

Kenneth Carrell
New Lenox, IL

Date of Birth: 09-03-1953
Single Lung Transplant 04-12-2008
Loyola University Medical Center
Date of Death: 08-19-2017

Deborah Ann Mohrmann
Green Cove Springs, FL
Lung Transplant 08-02-2015
Shands Transplant Center
Date of Death: 05-27-2017

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



Once all the margins are cancer free, the surgeon will then determine the best way to heal the wound. Typically, there are many options for this: some wounds do best by healing on their own without sutures though most will end up being repaired by bringing adjacent tissue together to close the wound gap with sutures, or by covering with skin from another part of the body in the form of a graft. The type of closure depends on the location, size and the tightness of the skin around the wound, patient's daily activity level and above all patient preference. It is a joint discussion and decision between the surgeon and the patient.

After the surgery, the wound is usually covered with a thicker pressure dressing. The surgeon and nurses will instruct the patient how long to keep the pressure dressing on. Typically, it should stay on for 24 to 72 hours. After that, the wound can be washed with gentle soap and warm water once daily and covered with either Vaseline, a prescription topical antibiotic cream or ointment of the surgeon's choice and a bandaid or another thin non-stick pad. Over the counter topical antibiotics such as Neosporin or triple antibiotic creams can lead to sensitization and allergies, and hence are no longer recommended. Patient should also avoid soaking the wound in hot tubs, swimming or any other activity that would immerse the wound in water for prolonged periods of time.

Depending on the location of the wound, running, jogging, yoga, Pilates, or any other intensive activity should also be limited within the first one to two weeks after the procedure to prevent potential rupture of sutures and subsequent wound dehiscence. Elevation of blood pressure and heart rate with intense physical activities can increase the risks of bleeding, therefore caution with these activities is advised after MMS procedures.

For pain management, most patients are able to control pain at the site with over the counter pain-relievers such as acetaminophen (Tylenol). In general, when the wound is well taken care of, the risks Mohs surgery is very low and the vast majority of patients do not experience complications.

Complex Skin Cancer and Mohs Surgery

As mentioned above, the vast majority of skin cancer can be cured with MMS. However, a small subset of more aggressive skin cancers may require other treatment in addition to MMS such as those with nerve invasion or very large and deep tumors. Additional treatments are usually planned as part of a multi-disciplinary treatment team that includes dermatologists and Mohs surgeons, radiation oncologists, head and neck surgeons and reconstructive surgeons.

Who qualifies for Mohs surgery?

While Mohs surgery has a very high cure rate as treatment for skin cancers, it is labor intensive and in some cases can take up most of the day and in some cases the same or similar cure rates can be obtained with other means of treatment. Hence, not all skin cancers are appropriate for Mohs surgery. The American Academy of Dermatology and the American Society for Dermatology Surgery Association have developed a set of Appropriate Use Criteria (AUC) that helps guide clinicians and surgeons when referring patients for Mohs surgery.

The AUC takes into consideration of the type of skin cancer, its location, size, depth of involvement, prior treatments and whether the patient is immunocompromised (as is the case for organ transplant recipients) or has genetic syndromes that predispose them to more aggressive skin cancers. Details of the AUC can be found on the American Academy of Dermatology website (www.aad.org).

In brief, the AUC recommends MMS for most non-melanoma skin cancers of face, hands, feet and genitals. It is also the treatment of choice for squamous cell and basal cell carcinoma of any location if they are large in size, recurrent, or have certain high risk features present in the initial biopsy. MMS is not recommended for pre-cancers or small superficial skin cancers on the body, arms, or legs.

What are the risks and how should the patient prepare for Mohs surgery?

Just like standard excision, risks of Mohs surgery include bleeding, infection, pain and scar formation. Since local anesthetics are used, patients usually do not experience pain or discomfort during the procedure. However, the initial injection of anesthetics can cause a brief burning sensation. The risk of bleeding depends on the location, size, depth of the skin cancer and whether patient is on any blood thinner medications such as aspirin, fish oil, warfarin, Xarelto or Eliquis. However, studies have shown that the risk of bleeding complications during or after MMS, is very low, even for patients on blood thinning medications. The same is true of risk of infection after MMS. In general, patients should take all their medications as usual unless they are instructed otherwise by their doctors.

To summarize, Mohs micrographic surgery is an excellent treatment option for many non-melanoma skin cancers. It is the treatment of choice for high risk skin cancers and for those on the more cosmetically sensitive areas. It offers very high cure rate and spares the most amount of normal tissue possible leading to excellent outcomes. The recommendation to proceed with Mohs surgery should be discussed with one's primary dermatologist and a Mohs surgeon.

A Celebration of a Life



For those of you who didn't know him, I want to introduce you to my friend, Ken Carrell. Ken joined Second Wind in July of 2008 and later he agreed to serve on the Board of Directors. He had received a single lung transplant at Loyola University Medical Center on April 12,

2008. and Ken wanted to give back to the transplant community that had supported him and helped him.

Ken earned an Associate of Science degree in Engineering from Penn State University in 1975; a Bachelor of Science degree in Business from Olivet Nazarene College in 2000; and a Master of Business Administration (MBA) degree from the University of St. Francis in Joliet, Illinois in 2004. Ken's engineering career was in the nuclear power industry and he was also the sole owner of Carrell Construction Management. Ken brought all of these skills and talents to the Board of Second Wind.

Ken agreed to take an officer's position of Vice President and to take on a project Second Wind had been thinking about, and sometimes working on, for several years – re-designing our web site. Hopefully all of you reading this article have been to our web-site: www.2ndwind.org. Many of you may also have been to our old web-site. The job of redesigning our web site was enormous. Our old web site had several tabs across the top of the home page and numerous sub-topics under each tab. It was almost impossible to find any information on the site.

Ken chaired a committee to redesign the site, with me and Tom Archer as committee members. It would be nice if I told you we split up the work evenly, but we didn't. The bulk of the work was completed by Ken. When I or Tom were assigned certain duties, Ken always followed up to make sure the work was completed. We needed someone to spear-head this project and to keep it moving forward. We had to decide what information to keep, what to get rid of, and what to update.

Second Wind obtained three bids from web designers in St. Louis, Mo; Columbus, Oh; and Chicago, Il. WebLinx of Chicago was selected as our design firm and Ken met with their staff to determine how to proceed.

It took a tremendous amount of organizational skills and computer knowledge to get this project off and running. Ken provided those skills and worked for months on this project. Ken left the Board in July of 2015 to pursue local interests and projects and to spend more time with his family.

Ken posted regularly on Second Wind's Email Support Group. There he shared his own transplant experience with others who asked questions. Many posting questions were pre-transplant and they needed to communicate with someone who had been through a lung transplant and was willing to share their own experiences. They wanted to know there was life after transplant and what that life was like.

Ken had many hobbies and passions. He was a member of Saint Jude Catholic Church in New Lenox and was also a member of the Knights of Columbus. He supported the New Lenox Boys Baseball; founding coach of the New Lenox Lightning Girls Competitive Fast Pitch Softball Team; and member of the New Lenox Cherry Hill Committee of 10. Ken was a lifetime member of the Penn State Alumni Association.

Ken's greatest passion was his wife of 35 years Patricia (Pat) and children: Drew Vanderploeg; Chad Vanderploeg; and Mary Carrell. Ken was also blessed with four grandchildren: Brynn, Kyler, Riles and Breck Vanderploeg.

On August 19, 2017 Ken passed away. During his nine plus years post-transplant, I know he felt truly blessed to have been given a second chance at life and blessed for the care he received from his family, doctors and staff who cared for him. He always encouraged everyone to "keep God in your life every single day." Ken loved life and lived it so that each day should be celebrated.

Rest in peace my friend. The pain is over and you are now with our Lord. God Bless you!

Cheryl A. Keeler
President, Second Wind

NEW MEMBERS

Scott Bieber
James Fanoni
Jack Norton
George Spatz
David Zylstra

Aaron Brooks
Rhonda Lyman
Lola O'Brian
Reana Woods

There were also ten (10) new members who wish to remain confidential.

MEMBERSHIP RENEWALS

Gary Bland
Marc Chelap
John Curtin
Diane Desiderio
Robert Glim
Michael Olson
Chuck Schuele
Susan Sweeney
Fred Triquet

Ken Carrell
Cathy Cuenin
Maggi Czoty
Doris Frick
Harlan Halvorson
Luanne Rizzo
Frank Shields
Robert Sharp
Paul Woods

There were also two (2) renewals who wish to remain confidential.

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



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bad things in life.**

**For they opened
your eyes to
the good things
you weren't
paying
attention to
before!**



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

Kenneth Carrell
Paul Woods

Chuck Schuele

Membership Fund*

Chuck Schuele

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

Financial Assistance Fund

John P. Curtin
Chuck Schuele

Harlan Halvorson

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

In Memory of Steven C. Schumann

by

Gary and Pamela Bland
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In Memory of Kenneth Carrell

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Laura Wallner

In Memory of Theresa Beth Monroe

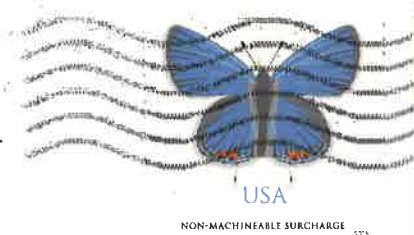
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(Events Calendar continued from insert)

Support Groups & Events Calendar

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

Ohio State University Lung Transplant Support Group
Comprehensive Transplant Center
770 Kinnear Road
Columbus, OH 43212

For directions assistance call:
614-293-8000
medicalcenter.osu.edu

Please call our office with any questions at
614-293-5822
Meeting last Tuesday of the Month 6:00 p.m. to 7:30 p.m.