

Reports Cast Doubt on Effectiveness of COVID Vaccines In Transplant Recipients

Recent reports in the New York Times (4/14/21) and the online journal JAMA revealed that individuals who are immunosuppressed might not obtain the full protection that the Pfizer or Moderna vaccines offer against COVID-19. However, remember that these are preliminary reports of studies that are still ongoing.

The list of those who are immunosuppressed includes organ transplant recipients, survivors of blood cancers and anyone who takes the drug Rituxan or the cancer drugs Gazyva or Imbruvica—all of which kill or block B-cells, the immune cells that churn out antibodies—or Remicade, a drug used to treat inflammatory bowel disease. It may also include some people over age 80 whose immune responses have faltered with age.

“...IMMUNOCOMPROMISED PEOPLE SHOULD STILL GET THE VACCINES BECAUSE THEY MAY PRODUCE SOME IMMUNE CELLS THAT ARE PROTECTIVE AGAINST THE DISEASE.”

The Leukemia and Lymphoma Society has set up a registry to provide information and antibody tests to people with blood cancers. And several studies are assessing the response to coronavirus vaccines in people with cancer, autoimmune conditions like lupus or rheumatoid arthritis, or who take drugs that mute the immune response.

A study conducted by Johns Hopkins University focused on transplant recipients, and included a total of 436 participants, none of whom showed evidence of a prior COVID infection. Their median time since transplant was 6.2 years, and all of the participants were on a maintenance immunosuppression regimen that included tacrolimus (83%), corticosteroids (54%), mycophenolate (66%), azathioprine (9%), sirolimus (4%), and/or everolimus (2%).

The study participants had received only the first dose of either the Pfizer or Moderna vaccine, and at a median of 20 days after that first dose, an antibody was detectable in only 76 (17%) of the 436 participants. These preliminary findings

of poor antibody responses in organ transplant recipients after the first dose of mRNA vaccines suggest that such patients may remain at higher risk for COVID-19 despite vaccination.

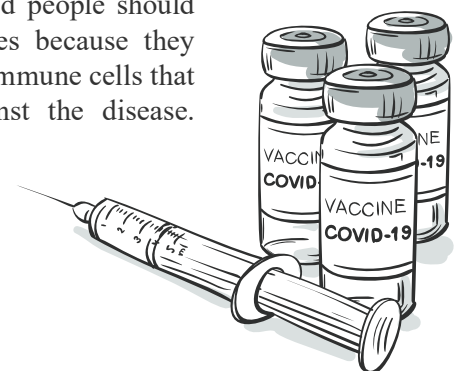
However, the researchers noted that additional studies of transplant recipients after full vaccination (two doses) to determine the characterization of memory B-cell and T-cell responses will be important in determining vaccination strategies and immunologic responses.

(Johns Hopkins is seeking additional study participants. Details on how to apply to be part of this research effort can be found on page 13 of this issue.)

Another option for these patients may be to receive regular infusions of monoclonal antibodies, which are mass-produced copies of antibodies obtained from people who have recovered from Covid-19. The Food and Drug Administration has authorized several monoclonal antibody treatments for people who have contracted Covid-19, but some are now being tested to see if they can prevent infections.

Dr. Tariq Ahmad, a gastroenterologist at the Royal Devon (England) and Exeter NHS Foundation Trust suggested that clinicians routinely measure antibody responses in immunocompromised people even after two vaccine doses, so as to identify those who also may need monoclonal antibodies to prevent infection, or a third dose of the vaccines.

Despite the apparently low odds of generating an antibody response using the current protocols, physicians suggest that immunocompromised people should still get the vaccines because they may produce some immune cells that are protective against the disease. Further study may well provide new approaches to better and more effective vaccine protocols.



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

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President's Notes

Tom Nate, President – Second Wind Lung Transplant Association, Inc.



I had planned to write an entirely different note for this issue, but then, without warning, we here at Second Wind experienced another devastating loss.

It was only several months ago that we lost Tim Adams, a valued Board member. Then suddenly, just weeks ago, we suffered the loss of one of

our longest serving Board members: Garry Nichols.

We on the Board remember seeing Garry at our last Zoom meeting, one that took place a mere week before he passed away. Needless to say, all of us are still in a state of shock.

Garry was an extremely valuable and active member of Second Wind and, more importantly, a highly respected member of the Board. He served on the Board since 2004, including two terms in the highly demanding role of Treasurer. He was a living repository of Second Wind history, one who had a wealth of knowledge about our organization. We are going to miss his calm, steady presence and the wisdom that he brought to our work for a long, long time.

The loss of our friend and colleague brings to mind the nature of the world that we live in as part of the lung transplant community. We deal with the loss of transplant friends more often than we care to remember, all the while understanding and accepting the delicate nature of the lives we've chosen as lung transplant recipients.

We are all well aware of the survival odds related to our surgeries, and of the side effects and issues we all will and have faced post-transplant. We both consciously and unconsciously

live each day with the reality that chronic rejection is possible at any time.

Many of us have lost close transplant friends and even family members. I myself experienced the loss of a sister who suffered from the same lung disease that I was diagnosed with, and who passed away only ten months after her transplant.

So we, as survivors, move forward with our lives, and work to honor those fellow transplant friends who have gone before us by living our lives, enjoying whatever time God grants us on this earth. We spend as much time as possible with family and friends, while also making an effort to serve others when needed.

Each time I lose a lung transplant friend or hear of the passing of one, while saddened, I am also reminded that I've been given an amazing gift, and should continue to live life to the fullest. By doing so I honor not only my fellow transplant friends, but also my donor and his or her family.

We each deal with the loss of friends in different ways, but it is in how we respond to the challenges in our daily lives that matters most. We at Second Wind will honor Garry's memory by continuing to build our organization to better serve our members. Helping lung transplant patients was one way Garry continued to serve others during his 16 years on our Board, and Second Wind is stronger today because of his leadership and service.

All of us on the Board wish to offer our most heartfelt sympathy and prayers to Garry's wife and family for their great loss.

Rest in peace, my friend.

Tom Nate,
President

Membership Dues Waiver To Be Extended

In 2020 the Second Wind Board of Directors voted to waive all membership dues through July 31, 2021. This action was taken in recognition of the economic effects of the COVID-19 pandemic.

Given that the pandemic's economic effects are continuing, the Board has decided to keep the waiver in place for the foreseeable future. Thus, new members can join Second Wind, and current members can have their membership renewed, both at no cost.

Note that current members will continue to receive renewal notices. This is in order to determine if there are any changes to your information, and to give you the opportunity to make

a voluntary donation in lieu of a dues payment, which many members have done.

Given that membership is currently available at no cost, it's a perfect time to encourage your caregiver, family, friends and/or medical colleagues to become a member of Second Wind. This will enable them to receive *AirWays*, our quarterly newsletter, and to avail themselves of other Second Wind services, as described on our website: 2ndwind.org.

The Board is grateful for the support of our members, and extends our wishes to all for continued good health and a safe summer season ahead.

New Study to Look at Impact of CMV on Adults Post-Transplant

Adelphi Values, a health research organization that works with pharmaceutical companies to assess the impact of health conditions and their treatments on peoples' lives, is conducting a study exploring the burden of cytomegalovirus (CMV) and its treatment on transplant recipients.

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

Adelphi Values is looking to speak with adults **18 years of age or older** who are recipients of a solid organ transplant, or an allogenic hematopoietic stem cell transplant (HSCT), **within the past five years**, and who have experienced a CMV infection that lasted for over two weeks despite treatment, or a CMV infection that came back after having been treated successfully.

Participation in the study will consist of a brief interviewer-administered questionnaire and a one-on-one, 60-minute telephone interview to discuss your experience with CMV infection, its treatment, and its impact on your life. Participants will receive \$120 for completing the 60-minute interview.

During this study, **no medication will be given or tested**. Your inclusion in the interviews will not replace or affect any care or assistance you are currently receiving, or may receive in the future. Your name and contact information will not be shared with anyone and will remain confidential.

If you wish to participate, or have any questions, please contact Samantha Power at Adelphi Values via email (Samantha.Power@adelphivalues.com) or by calling 617-399-9660, and referencing study number TK8701A.



Editor's Notes

- As noted in Tom Nate's "President's Notes", Second Wind suffered a great loss with the recent passing of Garry Nichols. Unfortunately, it happened just as this issue was going to print, and we didn't have time to fully acknowledge Garry's contributions to our organization. That will be remedied in the next issue of *AirWays*.
- Spring has sprung, and with it comes more time spent outdoors in the sun. This issue contains two important articles on how sun exposure, or the lack of it, can affect the health of organ transplant recipients. Check out these articles on pages 10 and 12.
- Our members have been enjoying a "dues holiday" since last summer, and the Board of Directors recently voted to extend it. You can find the details in an article on page 3.
- "In the past *AirWays* always included a long list of Support Group meetings, but the pandemic has changed everything. See page 15 for a list of groups that are currently meeting virtually. If your group is meeting be sure to contact me at phenry2ndwind@gmail.com so that we can include it in the next issue.

- Patrick Henry, Editor



Lung Diseases: A Glossary

By: Jane Kurz, Ph.D. RN & Dr. Kaymar Afshar, UC San Diego

Lung transplantation is a treatment for those with end-stage lung disease that is resistant to conventional medical therapy. The following four transplant procedures are available: single lung, bilateral lung, heart-lung and transplantation of the lobes from two living donors in select cases. Improved survival rates are noted based upon improved recipient selection, better immunosuppression regimens, and surgical and technological advances. Unfortunately, these do not result in a cure, so lung transplant recipients are required to take a lifetime of medications, undergo close monitoring and have strong caregiver support.

The following terms describe only some of the 80+ lung conditions that are suitable for transplantation. Note that the only way to determine if your situation meets the definition of one of these diseases is to meet with appropriate specialists, as often more than one field of expertise is needed.

Alpha-1 Antitrypsin (A1AT) Deficiency is an autosomal recessive (genetic) disorder that is commonly associated with Chronic Obstructive Pulmonary Disease or bronchiectasis. In addition to affecting the lungs, patients with A1AT Deficiency can also develop liver disease. A1AT is a protein that is produced in the liver and normally found in the lungs. It protects the lungs from a natural enzyme (neutrophil elastase) that is produced during inflammation from bacterial infections or smoking. A severe deficiency of A1AT results in premature destruction of the alveoli (air sacs) as seen on a chest X-ray, and a decline in lung function as noted on pulmonary function tests (spirometry). More information can be found at alpha1.org/what-is-alpha1/.

Bronchiectasis is a chronic disease that is characterized by permanent, abnormal dilation of the medium bronchi as a result of inflammation and subsequent infection. This damages the elastic and muscular structures supporting the bronchial wall, and results in airway obstruction. Patients with bronchiectasis can harbor various bacterial or fungal infections. The main goal of the recommended treatments is to reduce the amount of mucus plugs in the airways, thereby reducing the inflammatory and infectious processes. Primary ciliary dyskinesia is another condition that results in bronchiectasis. More information can be found at copdfoundation.org.

Bronchiolitis Obliterans (BOS) is a progressive airflow obstruction that can occur following lung transplantation. It is a major manifestation of chronic, irreversible lung transplant

rejection. This is typically monitored with pulmonary function tests (spirometry) and CT scans of the chest. Based on the degree of BOS, immunosuppressive treatments are modified to slow the progression of BOS.

Chronic Obstructive Pulmonary Disease-Emphysema (COPD) is a disease characterized by persistent and progressive airflow limitation, chronic inflammation of the airways and destruction of lung alveoli (air sacs). As air is trapped during expiration, the residual air trapped in both the small and large airways results in lower lung function, and gas exchange abnormalities resulting in increased carbon dioxide levels and reduced oxygen levels. More information can be found at copdfoundation.org.

Chronic Bronchitis is an independent disease that may precede airflow limitations. Unlike Emphysema, destruction of the alveoli is not seen in chronic bronchitis. Patients with chronic bronchitis show signs of inflamed airways on a CT Chest scan. More information can be found at copdfoundation.org.

Cystic Fibrosis (CF) is a genetic disease characterized by a defect in the transport of sodium and chloride from within the lung's epithelial cells to the cell's outer surfaces. CF affects the lungs, gastrointestinal tract, endocrine and even the reproductive system. As a result of genetic mutations, cells that line the lungs, pancreas, intestines and other organs produce secretions that are low in sodium content, making the mucus abnormally thick and sticky. The resulting mucus plugs cause organ scarring and, eventually, organ failure. The Sweat Chloride test was once considered the standard for diagnosis, but now genetic testing is the gold standard. In addition to lung transplants, there are newer genetic therapies that are helping to improve patients' lives. More information can be found at cff.org.

Eisenmenger's Syndrome is a congenital heart defect which includes a ventricular septal defect (a hole between the 2 ventricles), pulmonary hypertension with pulmonary artery enlargement, and increased size of the right ventricle. The increased pressure of blood flowing through the shunt increases pressure in the pulmonary artery. Over time, this increased pressure damages the smaller blood vessels in the lungs. This is treated with a combined heart-lung transplantation. More information can be found at rarediseases.org/rare-diseases/eisenmenger-syndrome.

continued on next page

Interstitial Lung Disease (ILD), also called “diffuse parenchymal” lung disease, it refers to more than 200 disorders in which the tissues between the lung’s air sacs (alveoli) are inflamed. Over time, irreversible lung scarring (fibrosis) results. Causes can include: inhalation of occupational and environmental toxins, certain medications, radiation therapy, infections and connective tissue disease. Often, the cause can be unknown at the time of diagnosis. More information can be found at pulmonaryfibrosis.org.

Idiopathic Pulmonary Fibrosis (IPF) is a chronic, progressive scarring of the lungs from an unknown (idiopathic) cause. Chest X-ray findings are often non-specific, so it is recommended to obtain a CT Chest scan to better identify the pattern. Pulmonary function tests show restriction and possibly poor gas exchange. A surgical lung biopsy is considered the gold standard for tissue confirmation, but there are times that a diagnosis can be made based on clinical and radiographic findings. A biopsy may not be pursued if there is a higher risk of complication compared to the benefits of the tissue diagnosis. More information can be found at pulmonaryfibrosis.org.

Lymphangioleiomyomatosis (LAM) is a rare lung disease in which muscle cells that normally line the airways and blood vessels invade the lung tissue, growing into the walls of the airways and causing obstructions. The air sacs also swell and form cysts which impact oxygenation and gas exchange.

It primarily affects women, and the cause is genetic or of a random, unknown nature. Women with LAM can have lung collapses (pneumothorax), fluid around their lung or in their abdominal compartment (chylous effusion). More information can be found at thelamfoundation.org.

Primary Pulmonary Hypertension (PPH) is characterized by elevated pressure in the lung arteries (pulmonary arterial pressure) caused by stiffness, damaged or narrowing of the lung artery. As the lung pressure rises, it puts a strain on the right sided chambers of the heart. Eventually patients with PPH develop shortness of breath and symptoms of right-sided heart failure, such as swelling in their legs (edema) or swelling in their abdominal compartment (ascites). There are multiple PPH medications used to slow down the progression of the disease. More information can be found at phassociation.org.

Sarcoidosis is a chronic disease characterized by the formation of very small clumps of inflammatory cells (granulomas) in one or more organs of the body. The more common sites of involvement are the lungs, lymph nodes, eyes, skin and liver. Treatment is based on the organ function and disease progression, with steroids being the mainstay of therapy. In some cases, patients will experience a spontaneous remission, but patients need to consult with their doctor to see if this applies to them. More information can be found at stopsarcoidosis.org.



World Transplant Games Goes Virtual

Because of the ongoing pandemic the World Transplant Games (WTG), originally scheduled to take place this year in Houston, Texas, were shifted to Australia in 2023. In lieu of an in-person event, the WTG will be a virtual competition that you can participate in wherever you happen to be.

The “2021 World Transplant Games – 5K AnyWay”, sponsored by Texas Medical Center, is a virtual race around the world that will take place May 28-June 4.

To create a team, join a team, or learn more about the 5KAnyWay see the ad on the back cover, or go to wtg2021.com.

A Perfect Match

By: Carole Gibson-Morton

My husband John and I met in late 1999 in an Internet chat room for those with Alpha-1 Antitrypsin Deficiency Disorder. Every evening ten or so of us would chat for a couple of hours. It was a Godsend for me as I was desperate for information about Alpha-1 and loved meeting others with the same illness. If not for meeting people in the chat room who had already had a lung transplant, I probably would never have considered it. That chat room saved my life in many ways.

Among the regulars in the chat room was a man who signed in as “THJohn”. He and I hit it off immediately—we had the same sense of humor and we were the fastest typists, which meant we had a lot of control over the conversation. After about six months of cyber flirting with John in the chat room, someone thought to ask him what the TH stood for. I had never thought to ask. When he said “Terre Haute”, I was pleasantly surprised as that’s only 100 miles from Evansville, Indiana where I live.

We HAD to meet in person!

Long story short, I was already very sick when we met; my FEV-1 was 27% and I was on oxygen. Though John’s lung function was low, in the low 30% range, he wasn’t nearly as sick as me. Then John ended up getting married, and I just kept getting sicker.

In 2003 I had a double lung transplant at IU/Methodist in Indianapolis. The surgeon told my family they were the best lungs he had ever transplanted. I went home after eight days and stayed alone in my house that night. I almost had to throw my mom out as I was determined to finally be alone and not have anyone hovering over me. The very next day I was out walking the neighborhood.

It was heaven.

As I was enjoying excellent health, John was maintaining his lung function, only using oxygen with exertion, but his marriage dissolved. His two adult children had moved on and he had no family or caregiver in Terre Haute. I told him I would gladly share my support people with him if he wanted to move to Evansville. He did so in 2010 and we married two years later.

By the time we got married I was starting to have some other health issues, especially lymphedema in my right leg. As for John, he eventually went on oxygen 24/7, but still got around just fine.

From the beginning, I had skin cancers routinely. They were always squamous cell and usually small and easily removed. But in 2015 I developed a persistent skin cancer on that same bad right leg, which eventually caused me to have it amputated above the knee.

But before the amputation I shocked all the doctors with a diagnosis of lung cancer, and was given 12 to 18 months to live. I almost didn’t get chemotherapy, but Danyel Gooch, my transplant coordinator, talked some sense into me, and inspired me to give it a try. She has saved my life more than once.

Needless to say, I didn’t die, and had my leg amputated a year later. However, while John was taking care of me, his lungs were getting worse and it came time for him to pursue transplant.

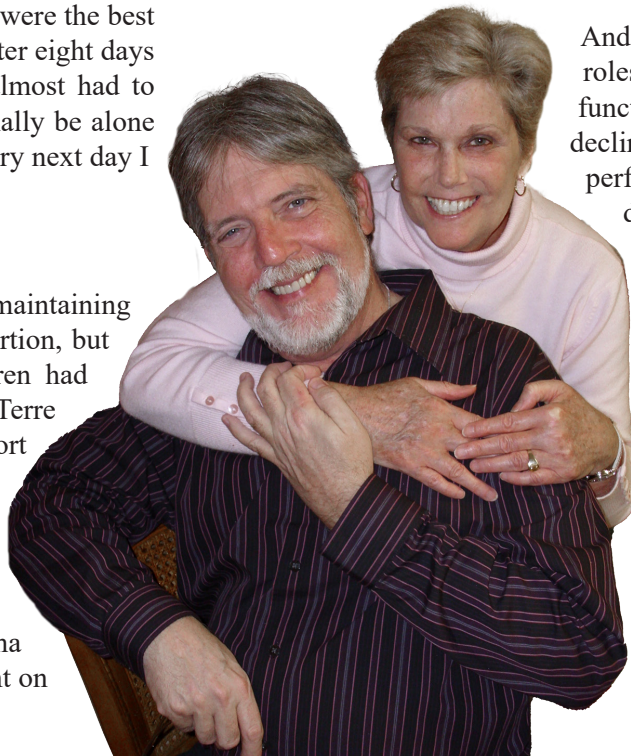
His lung transplant experience was so much different than mine, even though we went to the same transplant center (IU/Methodist). He was in the hospital for a month and had to stay in Indianapolis another three weeks for an intense, daily rehab program. My sister stayed with John as his main caregiver, with other family and friends helping out.

John now has 100% lung function, no health issues, and will be two years “out” in August. As for me, I will celebrate my 18th anniversary August 20, but I’m now in chronic rejection with an FEV-1 down to around 30%.

And so we have now changed roles. I had 100% lung function while his health declined and now he has the perfect lungs while my health declines.

Yet we somehow have a good life. We moved last summer to a house more compatible with my new wheelchair lifestyle.

We know we’re blessed, so thankful to have each other and taking turns being the caregiver, but mostly we’re just husband and wife, making the best of our golden years.



Honoring A Life

We imagine that by now you have will have noticed how many of the donations listed in each issue of *AirWays* come to Second Wind as a way to recognize the loss of a close friend or family member.

These “In Memory of” donations are a wonderful way to help Second Wind serve the transplant community, while honoring the memory of someone close to you who was either the recipient of a lung transplant, or acted as a caregiver for another who had been fortunate enough to have received this gift of life.



One way that individuals can generate donations in memory of a loved one is by listing Second Wind in the deceased’s obituary as the recipient of donations to be given in that person’s name. To do so, one need only refer such donations to be mailed to:

Second Wind Lung Transplant Assoc.
3590 Beckwith Lane
Crete, IL 60417

Anyone who sends a donation in will receive a thank you letter from Second Wind and, upon their request, we will send a list of all donors to the deceased’s family.

DONATIONS

Second Wind would like to thank the following individuals for their generous donation to help support our mission to serve the lung transplant population.

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In Honor of **Barbara Lenzini**

LaDonne Lenzini

Asthma Inhalers May Reduce Effects of Covid-19



A recent study reported in *The Lancet* showed that inhalers containing glucocorticoids such as budesonide may reduce the risk of severe disease and hospitalization in Covid-19 patients.

Inhaled medicines that contain corticosteroids act directly on the lungs to inhibit the inflammatory process that causes asthma.

Early studies of Covid patients showed that patients with asthma and chronic obstructive pulmonary disease (COPD) were significantly less likely to be hospitalized. Based on these, researches at the University of Oxford hypothesized that this could be due to the widespread use of medical inhalers in these patients.

Studies conducted in labs revealed that inhaled glucocorticoids reduced the replication of SARS-CoV-2 in lung cells, and also the expression of genes that facilitate the entry of the virus into the cell.

The researchers conducted a clinical trial in the UK involving 146 participants recruited between July to December 2020. Half of the people assigned to the group were asked to use inhalers that delivered budesonide along with usual Covid-19 care.

The team found that inhaled budesonide, when given for a short duration of time, could be an effective treatment of early Covid-19 in adults.

They found that clinical recovery was a day shorter for the budesonide group compared to the usual care group.

Meanwhile, the proportion of days that a patient had fever in the first 14 days was lower in the budesonide group than the usual care group. Furthermore, the proportion of participants with at least one day of fever was lower in the budesonide group.

Patients who received inhaled budesonide were also less likely to report persistent Covid-19 symptoms beyond 14 days.

The researchers concluded that early administration of inhaled budesonide reduced the likelihood of needing urgent medical care and reduced the recovery time after early Covid-19.

This effect, the team said, is equivalent to the efficacy seen after the use of Covid-19 vaccines. It is also better than any treatments used to prevent severe disease in hospitalized patients.

In Memoriam:

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

Robert King
December 2020

John Curtain
January 2021

Terry Stroud
February 2021

Garry Nichols
April 2021

It's Spring & Here Comes The Sun!

Mohs Micrographic Surgery: A Treatment Option for Skin Cancer

By: Dr. Juliana Gao and Dr. Diana Bolotin



Dr. Juliana Gao



Dr. Diana Bolotin

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 patients 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.

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 injection, 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 are 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

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.

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.

“...THE VAST MAJORITY OF SKIN CANCERS CAN BE CURED WITH MMS.”

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 band-aid 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 cancers 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 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 (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.

continued on next page

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 a 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.

Can Vitamin D Protect You Against COVID-19?

A research study at the University of Chicago indicates that higher Vitamin D levels appear to lower the risk of infection from the COVID-19 virus, at least among people of African-American descent. Additional studies are underway to determine the extent to which Vitamin D levels impact infection rates among all populations, and additional participants are being sought.

“These new results tell us that having vitamin D levels above those normally considered sufficient is associated with decreased risk of testing positive for COVID-19, at least in Black individuals,” said David Meltzer, MD, PH.D, Chief of Hospital Medicine and lead author of the study. “This supports arguments for designing clinical trials that can test whether or not vitamin D may be a viable intervention to lower the risk of the disease, especially in persons of color.”

Vitamin D levels of 30 ng/ml or more have been considered adequate, but the study showed that Black individuals with levels below 40 ng/ml were two and a half times more likely to test positive for COVID-19 than those with levels above that mark. There was no statistically significant difference found among White people.

Vitamin D is produced by the body's response to exposure to the sun, but such exposure can be dangerous for organ transplant recipients who are immune suppressed and subject to skin cancers. Thus, for this population the need for an adequate diet and/or the use of Vitamin D supplementation becomes important.

(For more information about skin cancers and their treatment via surgical intervention, see the article on page 10.)

While vitamin D supplements are considered relatively safe to take, excessive consumption is associated with hypercalcemia, a condition in which calcium builds up in the blood stream and causes nausea, vomiting, weakness and frequent urination. If left unchecked, it can lead to bone pain and kidney stones.

“Currently, the adult recommended dietary allowance for vitamin D is 600 to 800 international units (IUs) per day,” said Meltzer. “The National Academy of Medicine has said that taking up to 4,000 IUs per day is safe for the vast majority of people, and risk of hypercalcemia increases at levels over 10,000 IUs per day.”

(Note: The amount of Vitamin D supplements you ingest is a matter to discuss with your primary physician and/or transplant team.)

A team from the University of Chicago and Rush University has undertaken two studies to learn whether or not a daily vitamin D supplement can help prevent COVID-19, or decrease the severity of its symptoms. The Ingalls Development Foundation recently committed \$35,000 to help fund the study.

Individuals who would like to learn more about the study, or to determine their eligibility to participate, should visit the team's website at: chess.uchicago.edu/vitd/.

COVID Antibody Study Seeks Participants

Much has been written and said about the results of a study by Johns Hopkins Medicine (see cover story) that showed most organ transplant recipients did not develop the expected COVID antibodies from their first dose of the Pfizer or Moderna vaccine.

Those results are considered to be preliminary in nature, given that solid organ transplant recipients were not included in the first clinical trials for the COVID-19 vaccines, and that the participants in this study had received only the first dose of the vaccine.

Johns Hopkins is continuing to study the issue, and is seeking additional participants.

Titled, “COVID-19 Antibody Testing of Recipients of Solid Organ Transplants”, the study is offered at no cost to patients, and will use blood samples to measure levels of COVID-19 antibodies after vaccination.

Note that Johns Hopkins is not offering guidance as to whether or not you should receive the COVID-19 vaccine, nor will they provide the vaccine.

In order to participate in this study, or to learn more about it, please visit transplantvaccine.org and click on “Transplant Recipients”. There you will have the option to complete a sign-up form, and Johns Hopkins will contact you with more information.

Medicare Expands Coverage for Kidney Transplant Meds

In December 2020, a law was changed to provide lifetime Medicare coverage of immunosuppressive drugs for kidney transplant recipients. Before this, people who were only eligible for Medicare because of their end-stage kidney failure lost coverage for these vital medications 36 months after transplant. Now, anyone who meets certain criteria will qualify for lifetime Medicare coverage of their immunosuppressive drugs, regardless of age.

Anyone who meets the following criteria is eligible for indefinite coverage of transplant immunosuppressive medications under Medicare Part B:

- Received a kidney transplant from a Medicare-approved facility.
- Was eligible for Medicare at the time of their transplant and applied prior to their transplant.
- Does not have Medicaid or other public or private health insurance.

Unfortunately, this expanded coverage won't become effective until January 1, 2023. The National Kidney Foundation has announced that they will continue to work with pharmaceutical companies, state assistance programs and others to prevent gaps in coverage during this interim period.

Anyone having trouble affording these medications should contact the NKF Cares Helpline for assistance at 1- 855-653-2273 or via email to nkfcare@kidney.org.



Help is Just a Phone Call Away

Did you know that Second Wind maintains a 24/7 HELP line?

The phone line is manned (er...womanned?) by a caring volunteer named Cathy Cuenin, who is available to answer questions you might have about our programs and direct you to an appropriate resource to address any issues you may have.

While Cathy can't literally sit by the phone day and night, if she is unavailable to take your call you can leave a voicemail message and she will get back to you within 24 hours.

So the next time you find yourself with questions about Second Wind or the lung transplant process, dial 888-855-9463 and let Cathy HELP.

Transplant Anniversaries

FEBRUARY 2021

Name	Transplant Date	Years
Paul Albert	2/10/1993	28
Scott Dutenhoefer	2/11/2014	7
Karen Ettinger	2/1/2012	9
Cheryl Keeler	2/3/2005	16
Peg Matthews	2/16/2010	11
Jim McClure	2/24/2018	3
Erin Odell	2/11/1998	23
Raju Shah	2/22/2019	2

MARCH 2021

Name	Transplant Date	Years
Marla Brown	3/8/2020	1
Richard Hull	3/8/2016	5
Sharon Kelsay	3/19/2000	21
Robert K. King	3/20/2008	13
Edward Kuhn	3/4/2008	13
Judy Ludwig	3/14/2014	7
Blanca Iris Olivencia	3/24/2005	16
Lois Peddigree	3/2/2019	2
Sarah Ridder	3/15/2006	15
Reana Woods	3/9/2010	11

APRIL 2021

Name	Transplant Date	Years
Aunjelique Andersen	4/6/2019	2
Gary Bland	4/7/2009	12
Greg Briggs	4/30/1997	24
Kathryn Bryan	4/9/2016	5
Thomas Cook	4/11/2012	9
Mary Lou Dykas	4/7/2019	2
Teresa Figueredo	4/29/2016	5
Bobbie Hicks	4/23/2019	2
Rick Kamm	4/9/2008	13
Dylan Mortimer	4/13/2019	2
Jose Navarrete	4/25/2019	2
Ernest Pemberton	4/14/2016	5
Shiranne Simmons	4/8/2017	4

Second Wind Expands Presence on Social Media

Second Wind gives you two ways to engage with others who are interested in topics related to lung transplants, including the conditions that lead to the need for them and what the transplant experience is like, both before and after.

The newest outlet for discussions on these topics is Second Wind's new Facebook page which can be found at facebook/2ndwind.org/. There are currently 224 members and you can become one by going to that page and answering a few questions.

Recent postings on the page came from members being listed for transplant, those who successfully received one, and some who were rejected by one transplant center and seeking another option. Another posting publicized the Johns Hopkins University study on the effect of COVID vaccines on transplant recipients, and how to apply to participate in it (see page 13 for more information).

A second way to connect with other Second Wind members is through our Email Support Group (ESG). Participants post messages, and others can respond directly to that person or to the whole group. (However members never attempt to give medical advice.) Responses often trigger long conversations in which people share experiences, learning from each other, and some of these end up as articles here in *AirWays*.

Recent topics trending on the ESG include:

- How old is too old to qualify for a lung transplant?
- Do you use a spirometer at home to check your pulmonary function numbers?
- Have you been tested for antibodies after getting the COVID vaccine, and if so, what were the results? Did you know that antibody tests are available from Quest Diagnostics and CVS Pharmacies?
- Shared links to interesting articles on subjects such as "3D Organ Printing", "Research Into Organ Regeneration" and many others (thanks, Jeff Birgbauer!)

If you'd like to participate in future ESG conversations, or just listen in, contact Tom Nate at tmate1254@gmail.com.

Support Groups

UCLA Lung Transplant Support Group

Meeting virtually via Zoom; 1st and 3rd Mondays of every month from 12:30 – 1:30 PM

Contact emoran@mednet.ucla.edu for more information.

North Central New Jersey

Meeting virtually via Zoom on the second or third Wednesday of each month.

For information, call 732-412-7330.

Loyola Medical Center

Meeting monthly – for details contact one of the people listed below:

Susan Long, LCSW: 708-216-5454

Ashley Sieradzki, LCSW: 708-216-2151

Maria Diaz, LSW: 708-216-6527

New Members

The following individuals became members of Second Wind during the period February – April, 2021.

We welcome and thank you for your support of our mission.

Johnny Carter	Roseanne Best
Garry Ernst	Roger Daley
Richard Hull	Fernando Fernandez
Veronica Lobo	Kaitlin Gorman
Mike Malettte	Bryon Horton
Julianne Pease	Bethany McBee
Laura Roix	Erica Miller
Sheila Tate	Karen Volten

Jeffrey Anderson
William Anthony
Karen Cole
Mark Falk
Timothy Potocki
Sharon Pustejovsky
Ann Wysong

Membership Renewals

The following individuals renewed their membership in Second Wind during the period February – April, 2021.

We thank you for your continued support of our mission.

Timothy Groger	Betsy Cichon
Cheree Peirce	Fred Harris
Leslie Casey	Patrick Henry
Beth Davenport	Janice Laidlaw
Chris House	C. Lorenzo Pope
Michael Pazen	Charles Vigil
Jeanne Roberts	





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

Second Wind Lung Transplant Association, Inc.
75 Scattertree Lane
Orchard Park, NY 14127

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