

# THE STANFORD PFAC LUNG & HEART-LUNG TRANSPLANT NEWSLETTER

## PFAC

The Lung & Heart-Lung  
Patient & Family Advisory Council

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## OUR FIRST YEAR!

~ by Robert Duffy and Elyse Elconin-Goldberg, Co-Chairs

As the newest PFAC at Stanford Medical Center, our first year was extremely busy and wholly rewarding. We are continuing our efforts and dedication to improve your clinic experiences by providing healthcare tips and news in this bi-annual bulletin. We are very pleased to present this, our Spring 2020 edition.

*The Lung and Heart-Lung PFAC achieved three-out-of-three SMART Goals (Sustainable, Manageable, Achievable, Realistic, Timely) in 2019, publishing our first newsletter; conducting the first clinic wait survey; and, presenting the first Lung & Heart-Lung Transplant Education Day.*



Bi-lateral lung transplant recipient, author, health activist, hospice-care worker, and athlete, Isabel Stenzel-Byrnes, the 2019 PFAC Education Day Keynote Speaker

The beautiful Education Day last October at the Li Ka Shing Building brought together a life-affirming community of over one hundred-and-sixty transplant patients, their families or caregivers, medical staff, post-transplant patient speakers, and the entire PFAC, pictured above with guest speakers and lead administrators. Our second Transplant Education Day which had been scheduled for October 3, 2020 will be determined for the future due to Covid-19. There will be postings on the clinic bulletin board and on MyHealth.

Our PFAC is here to serve as your voice. If you have questions, feedback or suggestions please email us at: [DL-Lung PFAC@stanfordhealthcare.org](mailto:DL-LungPFAC@stanfordhealthcare.org). It is our goal is to work with the medical staff in order to continually improve your and your family or caregiver's understanding and experience of the transplant journey. We hope that you enjoy this issue! Thank you for reading it and please pass it along to share with others.



# The 2019 Lung & Heart-Lung Transplant Education Day and Luncheon

Photography by Kathleen Sheffer @ [kathleensheffer.com](http://kathleensheffer.com) and flower arrangements courtesy of Flower Divas, Santa Clara

# FOCUS Profiles

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## Joshua J. Mooney, M.D., M.S.

*Clinical Assistant Professor, Pulmonary & Critical Care Medicine, Stanford Medical Center*



Dr. Joshua Mooney has been a lung transplant attending physician at Stanford since 2015 and he currently serves as the Associate Medical Director for lung and heart-lung transplants. Some of us may have first known him as our interstitial lung disease physician, as he also routinely cares for patients with ILD. Dr. Mooney was born and raised in Minnesota and completed medical school at the University of Minnesota before heading west to California. He and his wife both completed their residency training at the University of California San Francisco before he came to Stanford for his Pulmonary and Critical Care fellowship training. There he developed an interest and expertise in interstitial lung disease and lung transplantation and he completed a Master's of Science degree in Human Services Research. This training helped inform his transplant research and has led to a number of impactful publications examining lung allocation policy and donor lung utilization within the United States. Dr. Mooney continues to be actively involved in research when not directly caring for patients. He is the recipient of many outstanding awards including the Medical Honor Society, Alpha Omega Alpha (AOA), 2008; and, the Transplant Registry Early Career Award from the International Society for Heart and Lung Transplantation in 2016. He resides in Belmont and when away from his work at the hospital he enjoys spending time with his wife, their son (age 6), and daughter (age 5). He can be found staying active in the gym or outdoors, coaching his kid's sports teams, and traveling. We are so fortunate that Dr. Mooney is on our healthcare team!

## Robert Duffy, PFAC Co-Chair

Bob Duffy is a double lung transplant recipient (three years post this October) and the current co-chair, along with Elyse Elconin-Goldberg of the Lung and Heart-Lung Transplant PFAC. You may have seen him engrossed in his e-reader in the clinic waiting room or you may have met him at one of the bi-monthly transplant support group meetings that he frequently attended. Bob was born with non-CF bronchiectasis (a trait he shared with his grandmother). Although plagued his entire life with the usual overabundance of phlegm familiar to CF and bronchiectasis patients, he was fortunate to enjoy relatively good health until his lung function began to slowly deteriorate in 2005. By 2016 he was on 24/7 supplemental oxygen and a succession of hospital stays that in May of 2017 led to his being listed for a bi-lateral lung transplant. Five months later he received the news that a match had been found! Thirteen days later he was home recuperating, and a few months afterwards he resumed working part-time from home as a software manager at NASA Ames Research Center. A few months later he resumed his regular full time work schedule (until the recent COVID-19 coronavirus situation). Like many of us, Bob works from home along with his wife and their college-age son, and he keeps in touch with his daughter who recently graduated from Humboldt State in northern California. In his spare time Bob enjoys reading, writing, playing the piano and rooting for the SF Giants. He entertained the group at last



October's Lung and Heart-Lung Education Day with popular tunes on the piano! Bob credits the success of his lung transplant to staying in the best shape he could prior to surgery; to the incredible skill and care of the Stanford transplant team; and, above all to the inestimable gift of his donor and their family.

# PFAC Bulletin Board

## *Transplant News, Tips, and Stories*



### CLINIC WAIT TIMES: An Update ~ by Jill Cooper, Jen Julian, and Mari Matsumura

Between March 11<sup>th</sup> and April 19<sup>th</sup>, 2019 PFAC conducted a patient survey and the clinic received over one hundred of your questionnaires about clinic wait times. The responses to the survey showed that on average, patients at the Lung and Heart-Lung Transplant clinics were spending just over two hours (2.2 hrs) between checking in and checking out at the front desk. Also, on average, more time was spent at clinics on Fridays compared to Mondays.

The results of the survey were forwarded to the lung transplant team and Dr. Joshua Mooney, Associate Medical Director of the program who is leading the instigation of better patient clinic experiences. The clinic team plans to make some changes in the near future. Beginning last March of 2019, for example, an additional clinic day of Tuesdays was added, which all patients may schedule.

### SUPPORT GROUP Meetings *ON HOLD*

*Regarding current Stanford Healthcare Center recommendations and Center for Disease Control guidelines for patients and families coming to healthcare facilities, our team is recommending that the Lung and Heart-Lung Transplant Support Group Meetings will be postponed until further notice. As proposed, the schedule remains the same with the hopes that we may have web presentations. Please check your MyHealth account for any updates regarding changes to the meetings, times, and speakers.*

The Lung/Heart-Lung Transplant Support Group meets bi-monthly as a resource for pre and post-transplant patients and their caregivers/support system. It is a space to share your experiences and ask questions without judgement. Given that lung and heart-lung transplant is a singular experience, we believe it is essential to provide a welcoming space to spend time with others who can truly relate to what you're going through and don't have to guess. Having this kind of process space is an integral part of healing for many of our patients.

The structure of the group is divided into two parts: 1.) something topical to the lung/heart-lung transplant experience; and 2.) time to process, talk, connect, and ask questions. Each group is moderated by at least one of the Lung/Heart-Lung Transplant Social Work Clinicians, but we aim to have all three of us there. Support group lasts for 1.5 hours and light refreshments are provided. We send a reminder email and a MyHealth message one month prior to group, and we hope to see you there! If you have any questions regarding support group, please feel free to email one of the Lung and Heart-Lung Transplant Team's social work clinicians: Hannah Gordon ([hgordon@stanfordhealthcare.org](mailto:hgordon@stanfordhealthcare.org)); Rosanna Tan ([rtan@stanfordhealthcare.org](mailto:rtan@stanfordhealthcare.org)); or Christine Doherty ([christinedoherty@stanfordhealthcare.org](mailto:christinedoherty@stanfordhealthcare.org)).

Facilitators: Hannah Gordon, MSW, 650-850-2049 and Rosanna Tan, MSW, 650-445-8867

**PROPOSED TOPICS:** May 6: *Presentation by Donor Family & Donor Network West* July 8: *Staying Strong Throughout Transplantation: Transplant Physical Therapist* September 2: *Keeping Healthy after Transplant: Transplant Nurse Practitioner* November 4: *Lung Transplant Program Update by Dr. Gundeep Dhillon, Medical Director*

# A STANFORD MILESTONE: *The 1000th Lung Transplant!*

~ by Tracie A. White for STANFORD MEDICINE NEWS, ed. Luanne McKinnon

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*The transplant team, they're my angels. They gave me a second chance at life.* ~ Alicia Bland

Alicia Bland's bi-lateral lung transplant was the 1,000th by the Heart-Lung & Lung Transplantation Program at Stanford Health Care since Stanford's first heart-lung transplant by cardiothoracic surgeon, Bruce Reitz, M.D., performed on March 9, 1981, just minutes past midnight. Mary Gohlke, a 45-year-old Arizona woman dying of primary pulmonary hypertension, was wheeled into a Stanford Hospital operating room for a heart-lung transplant surgery that would become a medical milestone. In the years since, about 250 heart-lung transplants and 750 lung transplant have been performed at Stanford Medical Center.

Bland's difficulty to breathe began thirty-two years ago when she was 22 and diagnosed with sarcoidosis, an inflammatory disease with no known cause that often results in serious damage to the lungs. Her doctor told her she had only about ten years to live. "I told my mother, don't cry," Bland said. "Doctors are often wrong. God had a different plan for me." She lived with the disease for decades, under regular medical supervision, but, unable to work and struggling to breathe. When her grandson was born three years ago, she was too weak to hold him. As the years passed and her lungs worsened, her doctors told her that she required a transplant and that she needed to move out of the San Joaquin Valley because of its poor air quality. Eventually, she moved to San Jose with her longtime friend and caregiver, Roscoe Little, and began visiting Stanford's pre-transplant clinic.

After two years, during a routine appointment, she received a phone call that, at first, she thought was a joke. She'd been on the waiting list to receive lungs for only about a month, so she was stunned. "They say they have some lungs for me!" she excitedly told her caregiver, Roscoe Little. Then she ran down the hall, barely able to breathe, to catch Joell Garner, RN, a pre-transplant coordinator who had been working with Ms. Bland for two years, preparing her for the desperately needed lung transplantation. "She stopped me in the hallway," Garner said. "It was amazing to witness. 'Oh my gosh. What do I do? They told me they have lungs for me.' She was completely breathless. I had to tell her to sit down." Twenty-four hours later, on Oct. 10, 2019, her diseased lungs were removed and replaced with the healthy lungs of someone who had recently died and donated their organs. Finally, she could breathe freely again!



Dr. Bruce Reitz leading the team of surgeons at Stanford during the first heart-lung transplantation in 1981



Ms. Alicia Bland with Dr. Gundeep Dhillon

*A lung transplant is something that truly takes a village, one that includes the patient; his or her caretakers; the donor and the donor's family; our interdisciplinary team of health care providers, including surgeons and nurses; a rehabilitation team; pulmonologists; dietitians; therapists; and more. It's an amazing team effort.*

- Dr. Gundeep Dhillon

Ms. Bland's surgeon, John W. MacArthur, M.D., assistant professor of cardio-thoracic surgery has stated, "we don't know if the lungs are good quality until a Stanford surgeon takes a look. [Ms. Bland's] surgery went very

smoothly, [she] had a really good recovery,” adding that he loves doing this type of procedure because of the improvement in his patients. “It’s challenging, but it’s very rewarding to see somebody who can’t breathe comfortably, or not well at all, go home and not need any supplemental oxygen.”

Dillon reassured Bland that her new transplanted lungs “look beautiful.” She couldn’t be happier with the outcome. Her breathing capacity increased from just 24% to a high of 82% within a few weeks after surgery. For the first time in thirteen years, she’s no longer attached to an oxygen tank. “Alicia, you’re doing great,” Dhillon told her the last time he saw her in clinic, “your lungs look beautiful.” “That’s so nice to hear,” she said, looking up with a smile.

**Further reading:** *I’ll Take Tomorrow: The Story of a Courageous Woman Who Dared to Subject Herself to a Medical Experiment—the First Successful Heart-Lung Transplant* by Mary Gholke with Max Jennings (1985).

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## YOUR MEDICATIONS

### *Being Prepared in Case of a Natural Disaster*

~ by Roy C. Lee, Pharm.D., BCPS

#### PLANNING STARTS BEFORE A DISASTER STRIKES



**BE PREPARED.** Disasters seem to be all too common now and with each new one more intense. As the recent fires in California and the COVID-19 pandemic have laid bare, such threats can leave us with our pants down and cause much anxiety when we are left without our life-saving medications. In such scenarios, we should all be prepared to know what to do. Here is a guideline.

1. **KEEP A CURRENT LIST** of your medications including dosages and refill information.
2. **KEEP A LOG** of how much medication you have.
3. **OBTAIN EARLY REFILLS** in the event your access to pharmacies may be limited (having early refills on hand will also allow you to keep a limited emergency supply at all times.)
4. **HAVE YOUR MEDICATIONS EASILY ACCESSIBLE** so that you can quickly grab them if you must evacuate.

If disaster strikes and you are without your life-saving medications and cannot go to your usual pharmacy, you should go to the nearest pharmacy available and transfer your prescriptions. In the case of major drugstore chains such as Walgreens or CVS, you can also change your pickup location online. In cases where this is not possible, many states permit pharmacists to make medically necessary exceptions during a declared state of emergency. In California, the Board of Pharmacy permits pharmacies to provide care by waiving requirements that may be impossible to meet during an emergency and to refill a prescription without a prescriber’s authorization if failure to refill the prescription might have a significant adverse impact on the patient’s well-being. However, depending on your insurance, you may have to pay out of pocket and seek reimbursement later. Other insurances will allow for emergency overrides once the pharmacy explains what is occurring. A website that may be useful if disaster strikes is Rx Open <https://www.healthcareready.org/rxopen>, which can help you find nearby pharmacies in areas that are impacted by the disaster. Rx Open displays the precise locations on **Google Maps** of **OPEN** pharmacies, **CLOSED** pharmacies, and those whose status is unknown.

# INSPIRING Lives

## Dominic Quagliozi

### *New Lungs and a New Baby*

~by Luanne McKinnon

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The Quagliozi Family

I first heard about the artist and fellow survivor of cystic fibrosis, Dominic Quagliozi from a Los Angeles art critic who told me about his watercolor series, “Objects in My Hospital Room,” 2012. As our destinies would have it, I met Dominic and his wife, the artist, Debra Bianculli at Stanford Medical Center where he was listed for a double lung transplant and I was there for my post-lung transplant clinic day. That was in 2014. Six years later, it is my honor to tell a bit about their extraordinary love story.

Dominic was first listed for a bi-lateral lung transplant at USC Hospital in April of 2012, four months before his marriage to Debra in an August wedding. At the time, he was being hospitalized every six to eight weeks for pulmonary exacerbations and even had to sit out their wedding reception for a few hours due to dehydration. Their challenges were immense. But, as Debra beamed about their utter happiness as newlyweds she also described how fraught their lives were due to her husband’s pulmonary decline.

Unlike ordinary newlyweds, “We couldn’t go more than four hours away for our honeymoon as we felt too guilty pressing the “pause” button on the opportunity to receive lungs. As the months,

droned on, and Dominic eventually needing oxygen 24/7, we realized we could be in it for the long haul and took some pauses to live life to the fullest as possible, on oxygen, on the list. It was like living at the edge of a cliff for three years, blindly, carrying everything you own, and your partner, and not knowing where the edge actually was that you could fall off of anytime. Where life included *baggage*, I carried it physically and emotionally (I think of my spirit animal as the donkey). I wheeled Dominic through airports, carrying two dogs in carriers, oxygen concentrator, the Vest, and our luggage.”

Dominic has said, “Trying to juggle impending lung failure with high points of life, finishing graduate school, newly married, in our twenties, always felt bittersweet. But, Deb and I always put love and admiration first. We really did live station to station, just getting through a challenge, or roadblock, then we’d figure the rest out.” Debra added, “we always saw ourselves as ‘spouse people,’ putting our partnership above all else so that whatever would come next could come from a solid, loving foundation.”

On June 24, 2015, after a three-and-a-half-year wait Dominic received two “pristine lungs,” according to his Stanford surgeon. But, shortly thereafter he developed cardiac problems, complications from diabetes and rejection scares. Despite those and prior to his gift of life with new lungs, the couple had begun to make fertility plans via the IVF process. As Dominic revealed, “part of the morbid reasoning was, I didn’t want to leave Deb alone in this world...wherever the post-transplant journey would take us.”

*It’s a hard thing growing up my whole life never thinking I’d love past college age, or find a partner, or get married, or need new lungs, let alone blow all those de-expectations out of the water and actually have a child! - D.Q.*

Their beautiful son, Thaelo Adagio Quagliozi was born in December of 2019. Dominic describes him as, “magical and glorious. It makes me feel like time travel exists - a connection to the future I couldn’t fathom and a past that now feels light-years away.” As for Debra, “I could never imagine the feeling of holding our child and looking into his eyes, and through it all - I’d do it again in a heartbeat knowing the love and amazement of what’s on the other side.”

# In Praise of CAREGIVERS

~ by Hannah Gordon, MSW, Cardiothoracic Transplant Department

It is difficult to articulate concisely the importance of your caregivers and your general support system during the pre-transplant evaluation process and the post-transplant recovery and continuum of care. Advanced lung disease and the lung transplant process can feel isolating and lonely, but with your caregivers and support system around you, you may feel less alone and vulnerable, bolstering you to tackle the arduous evaluation and recovery process. However, caregivers are often the unsung heroes during the transition into and out of lung transplant.

Caregivers can be easily overlooked, because much of what they do is in the “small” everyday tasks and hurdles: driving you to/from medical appointments; attending those appointments and the hours spent waiting for appointments to begin; providing emotional support and comfort; helping you to cook/clean/shop; and managing complex medications – and that’s just to name a few. Additionally, while acting as a caregiver, they need to take care of themselves. It’s no wonder we often say it’s just as hard to be a caregiver as it is to be a patient.

*So, we’d like to offer a round of applause to all past, current, and future caregivers involved in the healing process of lung and heart-lung transplant patients – thank you for the essential role you play and all you do.*



Lisa and Jim Malatesta

## Stanford Provides OUTSTANDING CAREGIVER SUPPORT

### Wellness Space at the New Stanford Hospital

An entire floor is dedicated to family and caregiver comfort, support, and education. At the center of the Wellness Space lies an oasis, a floor dedicated to providing support and comfort to the true heroes of healing—patients, families and caregivers.

### Interfaith Chapel, Gardens, Reading

The Family Resource Center provides compassionate support to caregivers and connects them with support networks and community resources. The Stanford Health Library offers complimentary medical research to facilitate a deeper understanding of diagnoses and available treatment options. The interfaith chapel and rooftop gardens create a welcome sanctuary, a place to pause and take a break from the clinical setting of the inpatient rooms above and the demands of the outside world beyond the hospital entrance.

### Nature + Art: The Art of Healing

*We think about patients, their loved ones and families and the staff. How can we create an environment that supports the patients’ healing... provides comfort to their families and offers relief to the complex and challenging work of the staff?*

~ Connie Wolf, consulting director of the art program

The new Stanford Hospital places equal value on the healing qualities of art and nature. “Today, every new hospital includes art,” said Connie Wolf, consulting director of the art program for the new Stanford Hospital. “Integrating art into the hospital environment allows us to think holistically about the healing of the mind, the soul and the spirit.” The new hospital places equal value on the restorative qualities of art and nature. It includes four acres of outdoor gardens, floor-to-ceiling windows in every patient room and more than four-hundred works of original art.



A work by the French-artist, Raoul Dufy in the hospital’s collection.



# NURSE COORDINATOR'S Corner

## YOUR ANNUAL Appointment

~ by Ellen Arce, Lindsey Clairmont, Bailey Mack, and Claire Reichle, Stanford Transplant Nurse Coordinators

Celebrating your annual "lung-iversary" is a momentous occasion! In addition to acknowledging this milestone, it is a time to discuss your other routine care. Approximately 3 months before your transplant anniversary date, call the Lung Transplant Clinical Clerical Coordinator (Lourdes Acevedo) at 650-725-2793 to schedule your annual appointment. Once scheduled, a letter will be mailed to you with detailed information regarding your comprehensive annual clinic visit. Please bring the completed paperwork to your appointment.

It is *imperative* that you have an established primary care physician (PCP). This care is separate from your lung transplant care but just as important. Studies suggest that organ transplant recipients are twice as likely to develop cancer and the risk for skin cancer is even higher! Due to these risks, routine care is very important. Results from your routine care and health screenings should be discussed with the lung transplant team to determine if any changes to transplant-related medications should be made.



-**Dermatologists** (skin doctor) should be seen at least once a year. Depending on findings, more frequent visits may be required.

-**Dentists** should be seen every 6 months. You will need to take a prophylactic antibiotic one hour prior to any dental cleanings/procedures.

-**Ophthalmologists** (eye doctor) should be seen annually to assess your vision and eye health.

-**Colonoscopies** should be discussed with your PCP. CF patients should have their first colonoscopy by age 30.

-Men should have a **prostate exam**, or PSA, annually.

-Women should talk to their PCP or OBGYN, about **mammograms** and **PAP smears** and their frequency.

-Due to the risk of osteoporosis a **(DEXA) bone scan** is ordered at least every other year to assess your bone health.

-For heart-lung recipients, at your first transplant anniversary a **cardiac catheterization with biopsy** is performed to rule out rejection of the heart. After your second year, a **dobutamine stress echocardiogram** will be performed annually to assess your heart health.

-A **bronchoscopy with biopsy** is routinely performed throughout the first year of your transplant and as needed thereafter.

# GERD and GASTROPARESIS: *A Lifestyle Article*

~ by John Clarke, M.D., Associate Professor, Medicine of Gastroenterology and Hepatology,  
Director of the Esophageal Program at Stanford Medical Center

Gastroesophageal reflux disease (or GERD) occurs when stomach contents flow back into the esophagus, or higher to the throat or lungs, and cause bothersome symptoms. It is relatively common and affects 20% of American adults on at least a weekly basis. Everyone refluxes to some extent. The average person has acid in their esophagus up to 4% of the time and can have up to 40 reflux events during a day. However, GERD is considered a problem only when it results in symptoms or complications.

For people who have had a lung transplant, however, GERD can be a serious concern as there is a risk that the stomach contents may reflux into the mouth and then go down into the new lungs (known as aspiration). This can cause irritation and inflammation to the new lungs, potentially leading to fibrosis and affecting overall function. Also, because the new lungs don't have the same nerve structure as original lungs, aspiration may be harder to clear and may not trigger the same sensation and cough reflex that would have been present prior to transplant.

After transplant, reflux may be more common due to a few factors. First, stomach emptying after transplant may be slower. This is referred to as gastroparesis and likely results from nerve stretching during the transplant procedure. Second, medications that are used after transplant can also affect reflux parameters. Third, a history of lung disease can also cause reflux due to pressure shifts and diaphragmatic strain.

Because symptoms do not always correlate with reflux severity, there are tests that we can perform to better evaluate whether reflux is present and, if so, quantify how much. In addition, we often will pursue a gastric emptying study to look at stomach emptying – as that can be a target for therapy to improve reflux. Medications, such as proton pump inhibitors and histamine-receptor blockers, are used to decrease acid production; however, these medications really work to decrease the acid in the reflux, rather than stopping the reflux per se. Lifestyle changes, however, work at decreasing reflux directly and are a key part of decreasing one's aspiration risk.

## Lifestyle Changes for Patients Diagnosed with GERD

There is a lot of data published on lifestyle changes for GERD, but if one sifts through the evidence there are a few things that really stand out as effective means of reducing reflux and subsequently the risk of aspiration:

*Avoid lying down within 3 to 4 hours of meals:* Most reflux events and aspiration events occur after meals and this can be worsened if the stomach empties slowly. A good protection is to eat dinner earlier and give yourself a few hours before lying down after eating.

*Raise the head of the bed:* As most aspiration events occur when lying down, the more protection from gravity you can supply against reflux the better. While you can use a wedge pillow or specialized bed, an easy solution is to raise the head of the bed with bricks, blocks or books. I generally recommend 2 to 4 inches as that is likely high enough to make a difference but not so high that you (or your partner) will be uncomfortable.

*Weight loss (if that is a factor):* Weight is a key driver of reflux (likely through increased abdominal pressure) and studies have shown that reduction in 5 to 10% of body weight can decrease reflux events. However, only focus on losing weight if you are overweight – if your weight is already optimal then decreasing it further will not be helpful and may cause other problems.

*Eat small low-fat meals:* Stomach emptying is based on the size of the meal and the fat content. If you eat small low-fat meals they will empty faster from your stomach and there will be less contents to reflux.

*Avoid trigger foods:* There is a long list of foods that are reported to cause reflux, including tomatoes, peppermint, coffee, alcohol, chocolate, garlic, onions and citrus. However, not all foods cause reflux in all people and cutting out all of these foods can be a challenge (and not always helpful). I recommend cutting out foods that seem to be clear triggers but would not cut out everything from the list unless you see that your reflux is worse when you take these foods.

*Make lunch your big meal of the day:* Most people have their largest meal at night and then sleep afterwards. While easier said than done, if your lifestyle allows you to make lunch a larger meal and have a smaller dinner this would be helpful from a reflux standpoint.

*This is not a complete list of lifestyle modifications that can be made, but I think these are the most important steps that one can take and these are the measures best supported by published data.*

# GUT INSTINCTS: A Perspective from Two Patients

## *Post-Lung Transplant Gastrointestinal Issues and Remedies*

~ by Mari Matsumura

I don't often tell people this, but one of my motivations behind getting a lung transplant was to be able to eat better. I was on a strict low sodium diet due to heart failure from my pulmonary hypertension. I longed for the day I could eat pasta, bread, and all the Asian food without obsessively watching my salt intake. So, I was beyond frustrated when three months after my transplant, I was still spending hours a day staring at my plate of food with nausea, cramping, and no appetite.

The good news is, treatments and diet can help! If you are having GI issues after transplant, you are not alone. Gastroparesis, or delayed stomach emptying, and Gastroesophageal reflux disease, also referred to as acid reflux, are both common post-transplant. It's important to let the transplant team know about your GI symptoms. Not only are GI symptoms uncomfortable/debilitating, but they could affect your transplanted lung or drug absorption. Seeing the GI doctor and dietitian was a turning point for me. A combination of medications and diet eventually relieved my symptoms to a point where I could return to work. Some Gastroparesis diet tips include (1.) pursuing a low-fat diet, (2.) avoiding fiber-rich/tough-to-digest foods like undercooked broccoli and asparagus, (3.) peeling off fruit skins, and (4.) chewing well. I recommend talking to your GI doctor or dietitian about what diet could help you best.

Lastly, meeting post-transplant peers who've had similar issues helped me gain more confidence and practical tips in dealing with these GI issues. The lung transplant support group is a great place to find peers who may share similar experiences as yours.

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~ by Luanne McKinnon

Imagine dreading every meal! Having lived in France and Italy, New York, Santa Fe and San Francisco, where cuisine is renowned, I confess to being a foodie. But, for close to ten years I suffered from severe (doubling over) abdominal pain, syncope or bouts of fainting from the pressure caused by undigested food, and, the feeling of being unable to control my life due to gastrointestinal problems. I could not keep dates to meet friends, schedule the hair salon, or even see a movie because I could never be certain that my digestive tract would not cripple me. My husband made normal meals and then ground them into "baby food" so that I might get proper nutrition. Gastro disorders impacted my mental health in the loss of a sense of "belonging" and general well-being that was especially frustrating in light of my miraculous new lungs! For many of us following lung or heart-lung transplantation have trauma to the vagus nerve—the longest and most complex of the cranial nerves that interfaces with the parasympathetic control of the heart, lungs, and digestive tract—which, is not an uncommon challenge. It is likely to cause mild to severely impaired gastric emptying or Gastroparesis, GERD, nausea, diarrhea, constipation, bloating and other complex issues related to digestive motility disorders. Gastric motility involves muscle contractions that move, or do not move food through the GI tract. The process functions through a set of coordinated signals between the brain (central nervous system); nerves of the GI tract, (enteric nervous system); and, muscles of the GI tract. In my case, the malfunctioning brought my life to a halt in many ways.

Over the years, I took various medications; and, I also relied upon acupuncture, massage, and breathing exercises for relief. When none of these were wholly sufficient to offset my neuro-gastrological problems I underwent a series of three separate botox injections to the stomach. Botox provided relaxation to my pyloric sphincter by expanding and calming the muscle thereby enabling food to empty more easily. This was a huge relief, but each injection only lasted about four months. Late in 2019, Dr. Linda Nguyen, Clinical Professor of Medicine in Gastroenterology at Stanford recommended a fairly new procedure, a Peroral Endoscopic Myotomy, known as POEM. This technique helps permanently relax tight esophageal muscles and open up areas of the esophagus and pylorus that, in my case, was closed. Stanford Medical Center is one of the first health care sites in the country to perform POEM surgeries. Mine was conducted by Joo Ha Hwang, MD, PhD, a leading gastroenterologist at Stanford who helped develop POEM. Under general anesthetic, the endoscopic procedure was minimally invasive with no wounds or stitches to the outside of my body. In only one week, I found great relief for problems that had plagued and debilitated me for years. For those of us who might benefit from POEM, we are very fortunate that Stanford is one of the few experienced health centers in the country to possess unrivaled expertise in the field. I am so very grateful!

# LIFETIME Self Care

## THE MASK DILEMMA

*Which One ? And, How to Use it Correctly!* ~ by Elyse Elconin-Goldberg and Robert Duffy

Wearing a mask will become a routine part of your post-transplant life, especially immediately after transplant. Even after you're out of the hospital and have returned home, masks will continue to be a part of your life. Over time you will probably hear and read various and sometimes conflicting advice about when and where to wear masks, and what they can and cannot do. While nothing in life is 100% certain, here are some general guidelines that all pre-and post-lung and heart-lung transplant patients should be aware of. There are four types of masks to consider when it comes to protecting ourselves in various environments, including hospitals, clinics, crowds, elevators, shopping malls, mass travel and especially in airports and airplanes and any other situation that warrants protection, particularly during the pandemic, flu and cold seasons. These are the N95, N99, surgical and respirator (NI00) masks that are described below.



Bi-lateral lung transplant recipient, Elyse Elconin-Goldberg and anonymous airline passenger using mask safety precautions

### N95 and N99 Masks



Bi-lateral lung transplant recipient, Larissa Morocco wearing an N-95 mask.

The N95 and N99 surgical masks are disposable and should be discarded when they get damp or moist. When there is fluid on the mask, water droplets with germs can be blown off and reduce infection control. The outside of a mask can get contaminated, so be sure to throw away the mask after use without letting the outside touch anything, and then wash your hands. Get a new mask if needed. N95 masks filter out 95% of small airborne particulate matter. Airborne pathogens attach to particles (droplets or dust in the air) and are effectively filtered out by the N95 Mask. N99 masks can filter up to 99% of airborne particulate matter. If convenient, consider getting fitted for a mask. The right size will create a seal between your face and the mask. Remember that weight gain or loss of 10 lbs or more will require getting refitted for your mask size. Also note facial hair, earrings, head scarves, wigs and facial piercings may impact the seal of the mask. N95 and N99 surgical masks are not designed for children

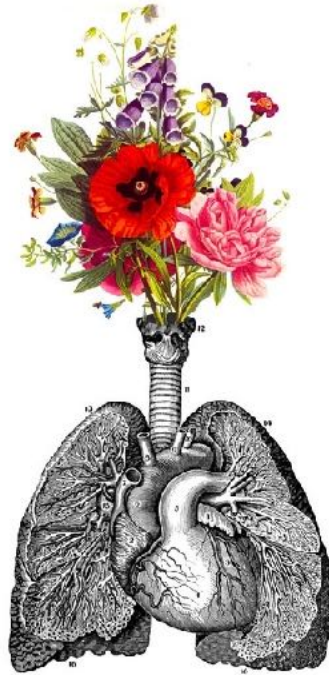
### Surgical Masks

These masks are the yellow or blue masks used by healthcare workers. They are useful for stopping the spread of germs when you are sick but do not provide enough protection from airborne germs, viruses and environmental irritants for transplant patients.

### Respirator Masks

These masks also need to be fitted to provide a seal with your face. Be aware that facial hair, earrings, head scarves, wigs, weight, and facial piercings may interfere with a good seal. Respirator masks are usually worn immediately after transplant when patients are most immunosuppressed. Transition to a less bulky mask can occur with time. These masks filter out 99.97% (essentially 100%) of small air particles and germs. Hence, these are sometimes called NI00. With time you will find that wearing a mask will become a routine part of your post-transplant life. Over time, continuing use of a mask will depend on your individual health and your progress post-transplant. This should be discussed with the transplant team and as always you should follow their direction. Working with the team you will be able to make the most of the Gift of Life and with this little extra effort, you will hopefully be protected for years to come.

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