January 8th, 2021

Dear Patients and Families,

For those of you new to our Program, it has become a tradition to send out a yearly "State of the Union" letter to all of our patients. In last year's letter one of the things I wrote was,*" boring can be good too, as it means stability*!". Yikes...who could have predicted the year we have just had in 2020! They say that hindsight is "20/20." Let's hope we can leave 2020 behind with a kick in the "hiney" and look forward to a much better, super-duper, back to near-normal and medically boring 2021.

Suffice it to say that this year has been tremendously challenging for all of us. As a program we had to pivot very quickly in March when the pandemic first hit our area. We all became "Covidologists" and "Zoomologists" overnight. COVID-19 shut down many things, including our clinic virtually overnight. We learned to conduct telemedicine visits on the fly, thus enabling us to maintain contact and take care of all our patients. Hopefully, our communications and availability were of comfort and support during a stressful time for all.

All of us were involved in addressing the crisis, either taking care of our own patients with and without COVID, helping out in the ICUs (Chris King, Vik Khangoora) or heavily wrapped up in COVID research. Four of our Nurse Coordinators with ICU experience were pulled into the ICU's to help out with the initial surge. Shout-outs not only to Becky Packer, Joanna Coughlin, Patricia Jackson and Shanna Guzman for meeting this challenge, but also to our Nurse Coordinators who remained behind to assume care of all our own patients during this time of crisis. The first patient with COVID-19 was admitted to Inova Fairfax on March 3rd. As the numbers took off and things shut down (including our regular research), I was asked to assume leadership for all COVID-19 related clinical trials within the Hospital and the Inova Health System. Through our team's collective years of experience with lung disease clinical trials, we were very well positioned to meet this challenge and assume this responsibility. All of us embraced the opportunity to lead the fight against the virus and I am especially proud of our research team for everything we have accomplished thus far (see section on Research).

We are by no means out of the woods and the stress remains, albeit a more chronic mid-grade stress -- made better however, by a shining visible light at the end of the tunnel in the form of the vaccines. Okay, I will answer the looming question that is likely in everyone's minds as you read this: "*Should I get the vaccine?"* The recommendation from all of us is a resounding "*yes, when it is offered to you."* At this point, we are not sure when that will be, but we will keep you informed as soon as we get more information. Please find more details on our COVID-19 vaccine recommendations in the next section of this letter.

For those of you who are skeptical about getting the vaccine, suffice it to state that everything we do in medicine, including how we manage all our patients, is based on an evaluation of risk to benefit. In this case, we believe that the benefits of the vaccine far outweigh the risk of getting COVID-19. Admittedly, neither vaccine has been studied in patients with significant lung disease, including transplant patients who are on immunosuppression. The unknowns are whether patients who are on immunosuppressive therapy will mount an effective immune response to the vaccine. Indeed, we won't know this unless patients like yourselves step forward to receive the vaccine. As you will read from our blurb below, it **is the recommendation of the International Society for Heart and Lung Transplantation for heart and lung recipients to receive the vaccine**. What I will share with you is that a number of us volunteered and were part of the Pfizer vaccine study, before anything was known about it in terms of efficacy or side-effects. Some of us (like yours truly) have since found out that we were in the placebo arm, while others like Dr. Brown, Dr.Aryal and our

3300 Gallows Road, Falls Church, VA 22042
P 703.776.2986

Transplant Director, Debbie Campbell, discovered that they received the active vaccine. Both Dr. Brown and Aryal have since had very close contact with family members who, unbeknownst to them, had COVID-19, and neither got sick. These instances are perhaps microcosms attesting to the effectiveness of the vaccine. I hope this helps you make your decision, since ultimately this will be a personal decision for everyone. No pressure!

COVID-19 has certainly tested all of our resolves and we thank you all for your many messages of support and your understanding as we have "muddled" our way through the year juggling schedules and clinic. I apologize for this lengthy document that follows this introduction, but there is some very important information that hopefully you will find helpful. It's only 27 pages, but what else is there to do during these COVID times!

Thank you for your support of our Program and for putting your trust in us. On behalf of the transplant and advanced lung disease team, warm wishes to you and your families and hoping you all have a happy, not too festive, and medically uneventful New Year!

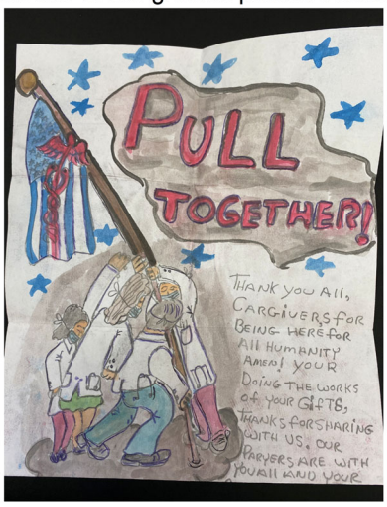
With warm wishes

Steve Nathan

Medical Director, Advanced Lung Disease and Transplant Program

Your friendly COVID-19 "eradication" squad

From one of our grateful patient's husbands



Noteworthy numbers

Post Lung Transplant Patients: Carlos Coronel: ltxreferrals@inova.org and carlcs.coronel@inova.org via phone 703-776-8049

New and Existing ALD Patients: Stephanie Vargas: ildreferrals@inova.org stephanie.vargas@inova.org phone 703-776-7939

New and Existing Cystic Fibrosis and Bronchiectasis Patients: Rosa Fuentes Uribe: cfreferrals@inova.org and rosa.fuentes@inova.org phone 703-776-7876

New and Existing Pulmonary Hypertension Patients: Monserrat "Mo" Cardenas: phreferrals@inova.org and Monserrat.cardenas@inova.org phone 703-776-6168

Medication refills: Phone Number is 703-776-2986, option 2, then option 3

ALD=advanced lung disease (includes all interstitial lung disease (ILD), including IPF, connective tissue disease-associated ILD, COPD, alpha 1 antitrypsin deficiency, sarcoidosis, and all other disease types not accounted for elsewhere.)

COVID-19 Vaccine Information for Patients:

There are currently several vaccine candidates for COVID-19 in development worldwide. Two of the vaccines (Pfizer, Moderna) have evidence that they are effective in preventing infection with symptomatic COVID-19 and both were granted emergency use authorization (EUA) by the FDA in December 2020. Allocation of these vaccines in the United States is guided by the Centers for Disease Control. The current allocation scheme prioritizes healthcare personnel and residents of long-term care facilities in the first phase of immunization (1a). As of December 31, 2020, people outside of those settings are not currently eligible for vaccine administration.

Phased Vaccination priority groups (CDC):

Phase 1a (current)	Phase 1b (ongoing)	Phase 1c (ongoing in limited fashion)
Healthcare workers	Adults 75+	Adults 16-64 with high-risk medical conditions
Long-term care facility residents	Frontline Essential workers (first responders, education, childcare, food & agriculture, corrections officers, transportation)	Adults 65-74 Other Essential Workers (construction, finance, IT, communication, public health workers)

*Please note, caregivers and family members will be vaccinated according to their own risk group, not the patients' risk group.

Details on available vaccines (Pfizer, Moderna):

Both vaccines use mRNA technology. Unlike many vaccines that use a weakened or inactive version of the virus to stimulate an immune response, mRNA vaccines do not contain any live virus so there is NO risk of it causing COVID-19. The mRNA never enters the nucleus of the cell and does not affect a person's DNA. The body contains enzymes that break down mRNA quickly, reducing chances for long-term side effects. Both vaccines require a series of 2 shots (21 days apart for Pfizer, >28 days apart for Moderna). The second "booster" shot is necessary to help develop full immunity.

Both vaccines together have been administered to more than 70,000 trial participants. The Pfizer vaccine is approved for people over the age of 16, and the Moderna vaccine is for individuals 18 and over. The main side effects after receiving the vaccine were injection site reactions, fevers, muscle aches, headaches, chills and joint pains that resolved within 1-2 days of vaccine administration. These side effects were more common and noticeable after the second dose.

Both vaccines appear to reduce the risk of infection with COVID-19 by ~95%. For context, most experts had hoped for a vaccine that was at least 70% effective. The 95% efficacy of the vaccine is comparable to the effectiveness of the chickenpox (92%), MMR (97%), and polio vaccines (99%).

Commonly asked questions:

- **Which vaccine should we get, the Pfizer or the Moderna?**
  The Pfizer and Moderna vaccines appear to be equally safe and effective, so you should get the one that is available to you first. You will likely not be able to choose and one is not better than the other.
- **Will we need to get a COVID-19 shot every year like the flu shot?**
  We currently do not know how long immunity from either of the vaccines lasts as they have only been studied for up to 6 months. Data on antibody levels over time is being collected on the clinical trial participants, which will help us know if additional doses will be necessary in the future.
- **Should people who had COVID-19 infection get vaccinated?**
  The studies did include individuals who had already recovered from a COVID-19 infection; thus it is recommended that even people who had COVID-19 also receive the vaccine when it is available.
- **Should immunocompromised patients receive the COVID-19 vaccine?**
  Neither trial included patients treated with immunosuppressive therapies. However, according to the current expert opinion, based on their mechanism of action, both vaccines are unlikely to trigger greater side effects for this patient population. The effectiveness of vaccines in immunosuppressed patients may be lower, as has been seen with other routine vaccinations. Concerns for increased

rates of rejection with vaccination in solid organ transplant recipients have not been proven in previous vaccine studies. The International Society of Heart and Lung Transplantation recommend that heart and lung transplant patients and their household members receive COVID-19 vaccination when it becomes available.

- **Do I still need to socially distance after getting both doses of the vaccine?**

  Once vaccinated, it is highly recommended that individuals continue universal mask wearing, hand washing, and social distancing regardless of vaccination status.

- **Vaccine Tidbits**

  1) It's ok to take Tylenol or ibuprofen for side effects, it will not dampen effectiveness of vaccine
  2) Should not receive any other vaccine (including influenza) within 2 weeks of either dose of the vaccine ,so please make sure you have your Flu shot already for this season in advance

We recommend COVID-19 vaccination for our patients.

Inova Health System will assist the Virginia Department of Health in vaccinating the general public as the vaccine becomes available by priority group. We will inform you of the details as we learn them.

Playing it Safe (taking the "Swiss Cheese" approach)

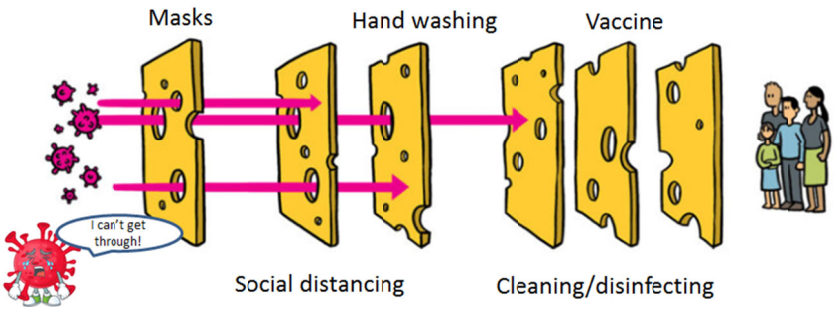
Nothing is perfect to prevent COVID-19; not even the vaccine is 100%. The approach to take is a layered Swiss cheese approach. As cheese-lovers know, Swiss cheese has holes in it, the analogy being that if there is one layer of Swiss cheese, the virus can find its way through. If there are two layers, then less likely, if there are three layers, then much less likely etc, etc. **What are the layers?** The first easy fix one is **social distancing**, and yes, even though 6 feet apart is touted as the distance to stay apart, this is not an absolute and 7 feet apart makes the "hole" in this layer even smaller and 8 feet apart, smaller yet.

The second is **wearing a mask** and making sure those around you (outside your immediate circle) are wearing masks when in your proximity, even if socially distanced. Hence now you have two layers of Swiss cheese in place. Then there is **hand washing, cleaning, disinfecting**… and coming your way soon, the **vaccine**! Vaccine information changes day to day. Please stay abreast of the latest developments through the two websites below.

https://www.inova.org/patient-and-visitor-information/covid-19-advisory?fbclid=IwAR3KwCnsqqjJg5ayji7a7fjvjBEEF2DxGz5mSFkuzlrObsgCORpR2WL-0jQ#vaccine

https://www.fairfaxcounty.gov/health/novel-coronavirus/vaccine/registration

The Swiss Cheese Model (or how to make Corona cry)



All layers are important, because each layer is not perfect.
The virus can get through when the holes "line up".
The more layers in place, the less likely the holes will align

Please see the end of the newsletter for Dr.Brown's personal experience receiving the COVID-19 vaccine.

Clinic Flow:

Last year I was writing about improving clinic efficiency; oh boy, how times have changed! This year, I am writing about how to keep clinic open safely for our patients and our staff. Due to COVID-19 precautions, we shut done in-person clinic effectively for about 2 months in the early Spring. We Zoomed with many of our patients and I personally found the Zoom visits surprisingly effective. Out of necessity comes great invention and in the spirit of trying to look for silver linings to the dark clouds, telemedicine home visits certainly emerged as one.

Advantages of the telemedicine visit include;

1. No long drives and Northern Virginia traffic to negotiate
2. No parking hassles
3. No need to "schlep" oxygen tanks
4. Sleep in later
5. No need for a companion to accompany, but others can join remotely based on each individual's wishes and needs.
6. Pajama visits

As a reworked COVID-friendly (or maybe it should be COVID-19 unfriendly ☺) clinic re-opened, close attention was paid to potential touch points for our patients on the way in and the way out. We tried to minimize and eliminate wait times in the waiting room, Most the chairs were moved out so that the waiting room now accommodates fewer patients. The waiting room is now mostly reserved for patients who have to be in the hospital for other testing. Telephone calls were initiated to patients waiting in their cars rather than have them sitting in the clinic wait room. Along these lines, we have tried to orchestrate any testing to be obtained on days prior to the visit to improve the efficiency and flow on clinic day. Not infrequently, patients were late to clinic through no fault of their own, but rather due to being held up by other same-day testing prior to their clinic visit. The advantage to patients of having the testing done prior is less time spent in the hospital on the day of the visit. In addition, this enables the providers to have the test and their results in hand, which makes for a much more efficient and productive clinic visit. Of course, we are totally sympathetic to our patients who have to travel from afar to see us, in which case we are happy for you to have your testing done the same day. Once patients enter the clinic, we have tried to work to minimize the time spent with us as well as orchestrating a one-way flow to patient traffic so that patients don't inadvertently "bump into" one another making their way around clinic. Rather than waiting around to make follow-up appointment, follow-up visits are booked remotely once you leave the clinic.

Clinic has been a work in progress with ongoing tweaking to improve the experience and efficiencies. We thank you for your patience and understanding during these trying times. Please know we are always there for you and will strive to provide the best and safest service no matter the circumstances.

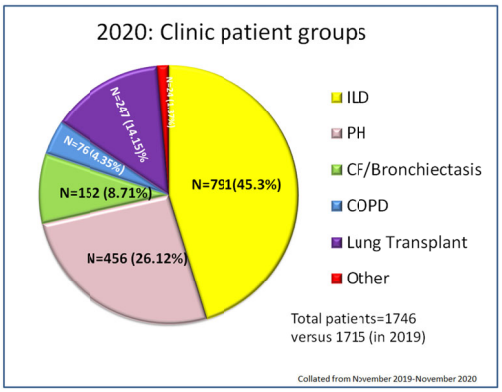
Despite the challenges of COVID-19 and essentially shutting clinic for a few months, we still managed to accommodate 3,683 clinic visits in 2020 (as of 12/24/2020) with 1508 being telemedicine visits and 2175 in-person visits. Despite this, the number of patients we follow continues to grow (n=1746 for 2020) vs. 1715 patients (a 1.8% increase compared with 2019). If one does the math, that means we saw our patients less often. While this is largely due to the circumstances, this does underscore that we continue to rely on co-managing our patients with your primary Pulmonologists and other providers.

We are grateful for your kind words of encouragement and appreciation!

The lung team bringing holiday cheer to our patients stuck in the hospital for Xmas!

Programs

As of December 2020, there were 69 CMS accredited lung transplant centers, 59 accredited Comprehensive Care Centers for Pulmonary Hypertension, 68 Pulmonary Fibrosis Foundation Care Centers, 118 Cystic Fibrosis Foundation-accredited Care Centers and 61 WASOG (Sarcoidosis) accredited Centers in the United States. We are proudly one of only18 programs in the Nation to hold all of these designations.



Personnel "Movers and Shakers section"

I reserve this section for welcoming new hires and acknowledging those who have left. However, I think I need to change the name since I think COVID-19 moved and shook us all! Maybe "comings and goings"...*nah, I still like movers and shakers.*

Thankfully, not much to report under this section in terms of "goings."

The docs did a lot of shaking, but thankfully no moving this year. Among all of our docs, we boast pretty extensive longevity (that mainly be me!) and tons of experience in the field. Our 7 full-time physicians have been with the Program a total of 58 years (Dr. Steve Nathan -24; Dr.Oksana Shlobin-15; Dr. A. Whitney Borwn-10; Dr. Chris King-7, Dr. Shambhu Aryal-4, Dr. Kareem Ahmad-4, and Dr. Vik Khangoora-2). Our surgical team continues to remain very strong under the leadership of Dr. Dan Tang, more than ably supported by our other surgeons including Drs. Liam Ryan, Eric Sarin and Ramesh Singh.

Who does what?

Below is the current division of labor between all our Nurse Coordinators and Advanced Practice. Providers (APPs) (APP's = the collective term for Nurse Practitioners and Physicians Assistants).

Team PH (pulmonary hypertension): Shanna Guzman, Johanna Coughlin and Alicia Echols.

Team CF (cystic fibrosis/bronchiectasis): Melissa Bowen

Team ALD (advanced lung disease): Becky Packer, Lauren Pickard. ALD covers patients with the various forms of interstitial lung disease (ILD), including IPF, connective tissue disease-related ILD, sarcoidosis, COPD and alpha-1 antitrypsin deficiency patients as well as other miscellaneous conditions. There is help on the way on the ALD side, with a 3rd Nurse Coordinator due to start in early January. We are very excited, but no one more than Becky and Lauren, to welcome Sholet Hampton to the team on January 21st.

Pretransplant: Patricia Jackson

Post-transplant: Michele Schreffler (also Lead Coordinator)

Inpatient ALD and PH APP: Nichole Sisserson

Inpatient Lung Transplant APP: Lauren Marinak

Inpatient Nurse Coordinator: Morgan Wahl

Outpatient Lung Transplant APPs: Meg Fregoso; Jessica Chun.

On the **research side**, we are saddened to lose Martha Alemayehu, who has taken a research job at the NIH. We wish Martha very well and I am sure she will do us very proud.

Our **Current research team** under the leadership of Edwinia Battle includes:

Merte Lemma, Claire Collins, Priscilla Dauphin, Rebecca Hays, Megan Harbor, Jen Pluhacek, ably assisted by Yoel Sanchez-Canales.

Lung Transplants:

Despite the challenges of the pandemic and having to shut our lung transplant program down for two months with the initial surge, we still managed to keep the transplant wheels turning with **28 lung transplants in 2020** compared with 32 lung transplants in 2019. This included only the third heart-lung transplant performed by our program over the course of almost 30 years.

2021 already promises to be a landmark year as we will be celebrating the 30th anniversary of our lung transplant program with the first lung transplant having been performed on 12/19/1991.

Based on the most recent data from The Scientific Registry of Transplant Recipients (SRTR), our average wait time for a transplant is 3.2 months, while our survival statistics continue to be in line with the National averages (See below under SRTR data, table C50). The Scientific Registry of Transplant Recipients is a government regulated website that provides full transparency for all transplant programs

around the country, with all kinds of data pertaining to the activity of transplant reported. I like to refer to this website as "the great equalizer," since each program's specific data is reported for the exact same period of time.

Most of the next paragraph is carryover from last year. Nonetheless, well worth repeating, especially for those new to the program and who are being considered for lung transplantation. One of the first questions potential candidates are interested to learn is how lungs are allocated.
Every patient that is listed for lung transplantation receives a lung allocation score (LAS). This is based on how sick the patient is and the likelihood of succumbing without a transplant with consideration also given to the likelihood of surviving a transplant. Under the most recent iteration of the allocation system, which has been in effect since November 2017, lungs are offered out in a 250 mile radius based on the site of the donor hospital. This necessitates higher lung allocation scores to draw lungs, which means that patients are generally quite a bit "sicker" at the time of transplant.
There are also certain diseases, notably COPD, where it is difficult to score high enough, no matter how compromised, to move up on the list. Invariably, lungs that do slip down to lower scoring patients are "marginal" or "so-so" on initial assessment and have been turned down by others. However, these lungs can frequently "turn around" and be used with very good and comparable results. To meet the demand for donor lungs, we now have **ex-vivo lung perfusion (EVLP)** available to salvage and recondition some of these marginal lungs. EVLP basically involves placing marginal lungs on a ventilator machine outside of the body for a period of up to 6 hours to see how much improvement in function can be attained before deciding if they are useable or not. This is being orchestrated through a research protocol in collaboration with Lung Biotechnology, a subsidiary of United Therapeutics, with the EVLP facility located in Silver Spring. Out of our 28 lung transplants this year, one quarter (N=7) were facilitated by the use of EVLP.
The term "marginal" lungs should not be confused with "increased risk" donors where there is a known risk factor for certain infectious diseases, such as HIV, hepatitis B and hepatitis C. What constitutes an "increased risk donor"? Examples include medical history not well-known, jail time, history of IV drug abuse, high risk sexual behavior etc. We routinely test the donors for HIV and hepatitis, but there is a theoretical short window of time when the blood tests might not turn positive yet. Since 2010, about 20% of our donor lungs have come from increased risk donors with no disease transmission to date. Rates of infection, rejection, and post-transplant survival have not been any different either. Thus, we feel very comfortable accepting most increased risk donors as they often have very high-quality lungs.

A unique advantage of our closely integrated ALD and Transplant programs is that we get to know and follow the patients closely in the pre-transplant period. This allows us to evaluate when medical therapy is failing and a lung transplant is needed. This has resulted in a very low waitlist mortality rate, which we believe is attributable to the care our patients receive pre-transplant, coupled with our aggressive pursuit of donor lungs when we get wind of them (pun intended ☺). We also tend to "push the window" in terms of giving our sickest patients the opportunity to have lung transplants. In fact ,many of our patients are in the hospital at the time they receive their lung transplants (See SRTR data below, 43.8% versus 12.3 % for the National average). These factors in concert result in our pre-transplant wait list mortality being **8.2% better than the expected rate** based on the SRTR data (Figure B4 below). For all patients considering transplantation, the question to be asked is not only *"What is my outcome likely to be after having a transplant?"* but also "*What are the chances I will ever receive a transplant with this program?"*. We pride ourselves on our outcomes, both pre- and post-lung transplantation.

SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS

Inova Fairfax Lung Transplant Program SRTR Highlights (August 2020 report)

https://www.srtr.org/reports-tools/program-specific-reports/

Figure B4. Observed and expected waiting list mortality rates: 01/01/2018 - 12/31/2019

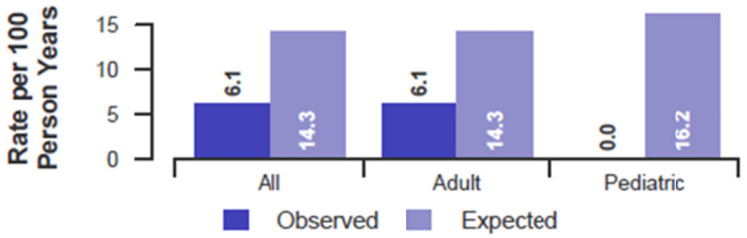


Table C2D. Deceased donor transplant recipient medical characteristics
Patients transplanted between 01/01/2019 and 12/31/2019

Characteristic	Percentage in each category Center (N=32)	Region (N=428)	U.S. (N=2,714)
Recipient Medical Condition at Transplant (%)			
Not Hospitalized	37.5	72.0	73.5
Hospitalized	43.8	12.6	10.3
ICU	18.8	14.3	16.1
Unknown	0.0	1.2	0.2

Table C5D. Adult (18+) 1-month survival with a functioning deceased donor graft
Single organ transplants performed between 01/01/2017 and 06/30/2019
Deaths and retransplants are considered graft failures

	VAFH	U.S.
Number of transplants evaluated	62	6,146
Estimated probability of surviving with a functioning graft at 1 month (unadjusted for patient and donor characteristics)	98.39%	97.25%

Table C6D. Adult (18+) 1-year survival with a functioning deceased donor graft
Single organ transplants performed between 01/01/2017 and 06/30/2019
Deaths and retransplants are considered graft failures

	VAFH	U.S.
Number of transplants evaluated	62	6,146
Estimated probability of surviving with a functioning graft at 1 year (unadjusted for patient and donor characteristics)	89.75%	88.89%

Table C7D. Adult (18+) 3-year survival with a functioning deceased donor graft
Single organ transplants performed between 07/01/2014 and 12/31/2016
Deaths and retransplants are considered graft failures

	VAFH	U.S.
Number of transplants evaluated	53	5,247
Estimated probability of surviving with a functioning graft at 3 years (unadjusted for patient and donor characteristics)	69.81%	72.55%
Expected probability of surviving with a functioning graft at 3 years (adjusted for patient and donor characteristics)	72.08%	--

Patient Expectations

I apologize for this "carry over" from my letter over the past four years, but a lot of this is well worth repeating.
For all our patients, it's important to understand that success depends on a team effort. We look at what we do very closely and are always looking to improve. This is typically in the context of our monthly Quality meeting, which is never short on agenda items. I do want to give a shout-out to our new Quality Manager, Adriana Kochi, who has really raised the quality (pun intended ☺) of these meetings beyond anything we have had in prior years. Adriana joined us from California right at the start of the pandemic. The "quid pro quo" is that we ask and expect our patients to do the best you can in helping us to help you (sounds like a line from the movie, Jerry McGuire ☺).
Patient-specific aspects of care that can impact outcomes include:

1) **Compliance** with all team requests, not running out of meds and taking all meds as instructed and when instructed.
2) Informing us of any **insurance** or employment changes,
3) **Keeping all appointments**. If you don't show for an appointment, then this "wasted' appointment slot could have been taken by someone else in need. We thank you all for your understanding and flexibility this year with the challenges imposed by the pandemic ,which has necessitated cancelled clinic visits or conversion to telemedicine visits.
4) Enjoying a good diet and **maintaining a healthy weight.**
5) **Exercise, exercise and more exercise.** This holds true for all our patient groups. This year has been especially challenging once again with gyms and Pulmonary Rehab programs closing down for periods of time. However, this is also an opportunity to be innovative. Some of you are fortunate to have exercise equipment at home, while others can map out a neighborhood walk or whatever else causes your pulse to race just a little for at least 20 minutes, at least three times per week. Personally, I keep a set of barbells under my desk for between Zoom activities.

Team requests for the New Year:

This section is like gastroesophageal reflux disease, most of these are also all repeat items!
1) With the start of a new year, please provide our office with any new insurance/prescription cards to avoid a lapse in your coverage.
2) Please try to understand if the Coordinators do not get back to you right away after a telephone call or email. The Coordinators have numerous callbacks every day, and frequently they only get to check their messages at the end of the day when all the clinic patients have been taken care of. For true emergencies, as always, please have the on-call Coordinator paged. (I think this is a repeater within the same letter-but an important point nonetheless!)
3) Email is a great way to communicate, please let your Coordinator know if this is convenient for you.
4) Know your insurance.
i. Know if you can have lab work drawn at Inova Fairfax or if testing needs to be done at an outside facility.
ii. Please make sure that you have the appropriate referrals (if necessary) before coming to see us.
5) If you have outside labs, please bring a copy with you to your next clinic visit as sometimes we don't receive these from the outside lab.
6) Similarly, if you have an outside CT of the chest, please bring the actual disc with you. We need to look at these ourselves and not just the Radiologist's report.
7) Please inform us of any significant changes in your medical condition, including hospitalizations at other hospitals.
8) Please make sure we have an updated list of your other doctors.
9) Know your meds! When you travel do so with a list of your meds, if you need to go to any Emergency room, please take a list of your meds.
10) If you have been set up to get a bronchoscopy, you might receive a call from Patty (Dr. Mahajan's scheduling coordinator. You will need an up-to-date COVID-19 test, as well as an up to date EKG and labs. There is a pre-procedure surgical services team available to facilitate this.

Our commitment to you:

We accommodate many different patients within our advanced lung disease programs. The purpose of these programs is to provide comprehensive care for our patients' lung disease. Our goal each step of the way is to provide individualized, high quality care, with a focus on maximizing patients' quality of life and extending longevity. In this regard we will strive to:

1) make sure that an accurate diagnosis has been obtained. In many cases this requires further testing. Sometimes the diagnosis evolves over time; therefore some testing might need to be repeated on a serial basis. We have a dynamic program, but patients themselves are dynamic and things change that might require new testing, repeat testing, review of old testing, change in the diagnosis (yes, this can happen!), and changes to medications.
2) focus on co-morbidities (co-existing conditions) that might have been missed and that we can treat. Many of the lung conditions are associated with co-morbidities that might impact patient's quality of life and affect their outcomes.
3) counsel patients about their diagnosis and provide an honest and forthright opinion of what the future might hold. We are not infallible in our prognostic outlooks and despite dealing with patients who have advanced lung diseases, we can never say, "You have 6 months to live" or "You should be good for at least 10 more years.". If nothing else, this year has taught us all how unpredictable life can be!
4) present the various treatment and other management options available
    a. Medications
    b. Pulmonary Rehabilitation
    c. Surgical options
    d. Palliative Care. The focus of this is to the patient's symptoms independent of anything done (or not done) to treat the underlying condition.
    e. Address **end of life issues**, including the possible role of Hospice Care. We may initiate these difficult discussions early in a patient's disease course. Please don't be upset by the initiation of such a discussion; it does not mean that your demise is imminent or that we don't have anything more to offer. Please think of it as akin to visiting a lawyer or paralegal to square away your last will and testament, which often takes place or should take place while folks are young, well and healthy.
5) provide access to and information about **clinical trials** of which we have many at any given time. Your clinic visit will quite typically include a Research Coordinator talking to you about any trial that you could qualify for. This is your opportunity to contribute to medical science, access new treatments before they are approved, and help future patients. The decision to participate in any clinical trial is entirely voluntary; we won't pressure you to participate, but rather are striving to inform you of all options. If you decide not to participate in a clinical trial, please be assured that this will in no way affect the care we provide. This year our research efforts got redirected towards COVID-19 (see section below on COVID-19).
6) perform medication reconciliations (creating an up to date and accurate list of current patient medications)
7) provide access to **support groups**, which are all Zoom support groups now.

Other miscellaneous clinic stuff:

8) We rely heavily on **co-managing** patients with referring physicians. For those patients who don't have a Primary Care Physician/Pulmonologist, we strongly encourage finding one. The only group of patients where we mostly function as the primary care service are our cystic fibrosis patients. We strive to communicate closely (primarily through our clinic notes) with your primary care physicians, as well as your other subspecialists. If you have provided the names of your physicians during the registration process, then these docs will automatically be sent our clinic notes once we sign off on them. If any of your docs are not getting our notes, please be sure to let us know.
9) Communication and questions: Please understand that we take care of many patients and try to accommodate everyone's needs. We have a 1:170 outpatient Coordinator to patient ratio. We ask for your understanding if our Coordinators don't get back to you right away when you leave a message or send an email. Our Coordinators are frequently busy with clinic visits during the day and only get to their messages and emails when clinic is complete. If it is truly an emergent situation, then please call 911. If you need to talk to someone ASAP, then please page the

on-call Coordinator. Please don't misuse this option either (for example, for medication refills, see page 2 for refill line telephone number). Similarly, if you have questions that are best addressed by a physician, I encourage folks to keep a running list so that these can be addressed at your next clinic visit.

10) Labs/blood draws: We no longer will draw routine labs in our clinic. The little phlebotomy room where we used to draw labs has been repurposed due to our new COVID restrictions and need to keep patients apart. We ask that you **have your labs drawn outside of clinic** a few days prior. This will help facilitate the clinic visit as we should have the results in hand when we see you. Labs can be drawn at any outside lab facility including Quest/Lab Corp or at any of our Inova's off-site lab facilities, which can be located at https://www.inova.org/our-services/inova-laboratories/locations
11) MyChart status: This is an update from Min Ahn, our clinic manager. We here at Inova are working to add 100% of our patients into our MyChart network. MyChart is part of our Inova EPIC EMR (Electronic Medical Record) system and it will serve as the central hub for video visits, communicating with your healthcare providers, viewing test results, and scheduling future appointments. The system is still new so we are continuing to improve access and use of the MyChart system. Specifically, we are working to improve the timeliness of our responses, access to your clinical after-visit summary notes, and access to your lab results. There will inevitably be some speed bumps ahead but we are working on fully integrating MyChart to ultimately improve the efficiency and privacy of your care. If you have any constructive feedback on how we can improve upon it, please call our office and help us evolve this system to better serve you! Thank you. (Transplant Office: 703-776-3281)
12) If we feel that you are stable and we are not really adding to your care or follow-up, then we might look to discharge you from our clinic. This is usually a good thing, so please don't interpret it that we don't like you anymore ☺.

Inova Advanced Lung Disease and Transplant Program: Provider Education

Most of this is repeat stuff, too. One of the missions of our Program is to educate the next generation of doctors, nurses, nurse practitioners and other healthcare providers. Frequently, you will be seen first by a Resident or Fellow, so please be patient as an extra set of eyes, hands and a sharp, young mind invariably results in better, more thorough and comprehensive care. Please don't be frustrated if you are asked the same question twice or even three times (we are not testing your resolve and patience☺).

We have fellows and residents rotate through with us from Carilion Health System (Roanoke), Eastern Virginia Medical School (Norfolk), Georgetown, George Washington, Howard, Walter Reed, and Washington Hospital Center. In 2020, we had 29 Fellows and Residents rotating through with us. We are currently in the fifth year of our Advanced Lung Disease and Transplant fellowship. This year our Fellow is Dr. Anju Singhal, who we are hiring permanently. Dr. Jean Pastre, our French Pulmonologist who joined us for a year of research, had to cut his time with us short as he got called back to his Hospital in Paris to help out with the pandemic there. Nonetheless, Jean remains part of our research team with a number of ongoing projects that we are managing remotely. Jean has first authored two original research papers that have been accepted for publication and more to follow, hopefully. Our summer student research program also took a bit of a COVID-related hit, with the hospital understandably and rightfully putting the kabash on volunteers in the hospital. Nonetheless, we did have 4 student volunteers who collated data remotely.

Patient Education & Support Groups

Transplantation. We hold a monthly transplant support group to which all our pre-transplant and post-transplant patients are welcome. It is an *expectation and requirement* that our listed patients attend this as it also functions as an education forum with specific topics and speakers on a monthly basis. Attendance is taken and failure to attend these can jeopardize you staying on the transplant list. We used to cut folks a little bit of slack with these, recognizing that many of our patients had to travel a distance to get to the hospital. One of the silver linings of the pandemic is that these are now all Zoom meetings, so any candidate can participate no matter where they are.
Please see below for the **2021 schedule**. For those folks who are "early" for transplant, it is still a good idea to attend. You do not have to be a transplant candidate or interested in transplant to attend any of these. Please bear in mind that the average wait time for a transplant at Inova Fairfax is in the range of 3-4 months. Therefore if you wait to be listed before attending these meetings, you may only have the benefit of hearing a few of the 11 excellent annual topics!

Cystic Fibrosis. In June 2019, a few CF patients and care team members started a CF Patient Family Advisory Board (PFAB) to help improve the CF patient experience and drive quality improvement through education, outreach, and dialogue. If interested in joining the monthly group meetings (virtual) or for more information, please email: inovacfpfab@gmail.com or talk to Elizabeth Davies-Wellborn (SW).

IPF. This support group is called the Pulmonary Support Group of Metropolitan Washington DC and is a monthly forum for not only IPF patients, but also those patients with any form of pulmonary fibrosis or interstitial lung disease. Patients do not have to be our clinic patients in order to attend. This support group is now supported by the Pulmonary Fibrosis Foundation and takes place the 4th Tuesday via zoom.

Pulmonary Hypertension. There are also patient run PH support groups for all patients with any form of pulmonary hypertension. There are two Pulmonary Hypertension support groups in the area; one in Virginia (NOVA@PHASupportGroups.org) and one in Maryland (MD-SouthernMD@PHASupportGroups.org)

See schedules on the next page.
For any information pertaining to our Support Groups, please contact our Social Worker, Susan Perry at susan.perry@inova.org

Agenda for Education Group
Heart and Lung Transplantation
Ventricular Assist Device, VAD
Inova Fairfax Hospital: Heart and Vascular Institute

2021

January 5	Pulmonary & Cardiac Rehab	Rehab Staff
February 2	Cardiac Transplant	Shashank Desai, MD
March 2	Lung Transplant	A. Whitney Brown, MD
April 6	Post-Transplant Care	ICU/3rd Floor Nurses
May 4	Dermatology	Jennifer DeSimone, MD
June 1	Clinic and Meds	Post Nurse Practitioners
July 6	Life Planning	Social Workers/Palliative Care
August 3	Living With a Transplant	Patient Panel
September 7	Waiting for a Transplant	WRTC Organ Procurement Org.
October 5	Health Insurance Issues	Financial Coordinators
November 2	Nutrition	Transplant Dietitians
December 7	Infectious Disease	Infectious Disease MD

Zoom meetings are the first Tuesday of Every Month from 1:00 to 2:00.
Please contact Elizabeth Davies Wellborn, at 703-776-8027 or email, elizabeth.davies2@inova.org, to receive the Zoom invite.
****All listed candidates need to call (703) 776-8027 if unable to attend.**

FIND SUPPORT. GET SUPPORT. GIVE SUPPORT

Pulmonary Fibrosis Support Group of Greater Washington DC

Date: Fourth Tuesday of every month via zoom
Time: 12:30-2:00
(12:30-1:00 eat lunch/socialize, 1:00-2:00 speaker)

If you or a loved one has been affected by pulmonary fibrosis, you are invited to attend our support group. Participating in a support group may improve your emotional well-being and have a positive impact on your health by offering you an opportunity to connect with others who are facing similar experiences, obtain practical information, and to receive support.

	SCHEDULE	2021
January	26	Palliative Care and Advanced Directives
February	23	Pulmonary Fibrosis and Pulmonary Hypertension
March	23	Pulmonary Rehabilitation
April	27	Lung Transplantion
May	25	Gastroesophageal Reflux Disease
June	22	Research and Clinical Trials
July	27	American Thoracic Society "ATS" Conference Update
August	24	Supplemental Oxygen
September	28	Symptom Management: Coughs
October	26	Nutrition
November	24	PFF Summit Recap
December	No Group	Happy Holidays!

Contact:
Susan Perry, LCSW, CCTSW
Disease Management/Transplant Social Worker
Advanced Lung Disease and Transplant Program
Inova Fairfax Medical Campus
3300 Gallows Rd, Falls Church,Va. 22042
Phone: 703-776-5776
Email: Susan.Perry@inova.org

For more information about pulmonary fibrosis, visit pulmonaryfibrosis.org.

Pulmonary Fibrosis Foundation

Support Group Website: www.pf-va.org
Facebook: Pulmonary Fibrosis Support Group of Greater Washington DC

GAME SHOW: In keeping with the times, the name of the game this year is "Behind the mask." Who are these people?
2020 was the year of WTF! (Wear the facemask ☺)
(Answers at the end.)

INOVA ADVANCED LUNG DISEASE & TRANSPLANT RESEARCH:

The first part of this section is a carryover. The Advanced Lung Disease Research Program was established in 1996 and has grown exponentially since then. Our site participates in numerous clinical trials for a variety of lung diseases including interstitial lung disease, lung transplantation, pulmonary hypertension, chronic obstructive pulmonary disease, and non-CF bronchiectasis. This includes industry-sponsored clinical trials, Inova investigator initiated studies, and research collaborations.

The research program's infrastructure includes:

- 4 research nurses
- 4 clinical research coordinators (CRCs)
- 1 research assistant
- 1 regulatory coordinator

Three of our research staff members (2 nurses/1 CRCs) are certified as Clinical Research Coordinators through the Association of Clinical Research Professionals (ACRP) and 1 CRC is certified as a Clinical Research Professional through Society of Clinical Research Associates (SOCRA).

Extensive experience with recruitment strategies in pulmonary trials as well as the tight integration of our clinical and research teams promotes effective communication with each other and patients. Every patient who is seen in our clinic is screened for available clinical trials on a daily basis by our research assistant. Our physicians personally discuss the importance and merit of clinical trial involvement, which raises patients' comfort and interest in participating. Our team's willingness to collaborate with sponsors and other institutions has led to exciting and novel studies.

And then the COVID pandemic hit, and our regular research was temporarily suspended. One would think that the "quid pro quo" of being in healthcare at the time of a pandemic would be job security. Not so much, as Inova was forced to make some tough decisions in order to ensure fiscal viability. Our research program "took a hit" with our biostatistician being laid off. Many thanks to Scott Barnett who facilitated much of our research productivity. Fortunately, Scott did find another job at National Children's Hospital. Another research casualty was our Clinical Trials Unit on 4 South in the Inova Heart and Vascular Institute, which was converted almost overnight to a dedicated COVID-19 unit.

As mentioned at the start of this letter, our research got redirected to address the COVID-19 pandemic. Initially, things moved very quickly as we tried to keep up with the speed of the virus. Together with Inova's Executive VP for Research, I co-chaired a daily COVID research meeting with key stakeholders to make sure we would get COVID studies up and running as quickly as possible. From first contact with the first Company who was running one of the first clinical trials (Regeneron) to the first patient getting randomized within the study was exactly one week, which is unprecedented as this is usually a 3-to-6-month process. What a change it was transitioning our research from rare diseases to dealing with and recruiting patients into COVID-19 clinical trials. Whereas with IPF and PAH, we would be doing well to recruit 1-2 patients/month, with COVID-19 we have been recruiting 1-3 patients per day into various treatment trials. Below is a summary of the COVID-19 studies we have participated in thus far:

1. Clinical trials. We have been approached to be involved in more than 120 clinical trials over the course of the last 9 months, so obviously we had to be very selective in those we choose.
2. "Homebrew" interventional studies;

a. Convalescent plasma trial. At the start of the pandemic Whitney Brown wrote the protocol, obtained a unique FDA IND and enrolled…donors and …recipients. This study was very time-consuming and complicated as it involved 4 different services to orchestrate (Advanced Lung Disease, Inova Fairfax Aphoresis, Inova Fairfax Blood Bank and Inova Blood Services). Through this, we were able to ease the load on our Hospitalists and Intensivists in terms of offering this therapy to our COVID patients.

b. Inhaled nitric oxide (iNO). This is an example of adapting what you have and what you know to the crisis on hand. We are a study site for an ambulatory device for the continuous administration of inhaled nitric oxide. In addition, I am privileged to be the chair of the steering committee for the sponsors study using this platform in patients with ILD. Thus I was in the position to put in for a FDA emergency IND (investigational new drug) during the initial stages of the first

COVID-19 wave. This led to 12 hospitals in the US similarly applying for FDA INDs. Before long, we had 120+ patients treated with this portable iNO delivery system (publication pending). This quickly led to a phase 3 program conducted at multiple sites throughout the USA. Unfortunately, the study was stopped early by the DSMB based on a futility signal seen after an analysis of the first about 110 patients enrolled. At the time it was halted, this study had enrolled over 190 patients…more to follow in terms of the results, but don't hold your breath for anything positive to emerge based on the interim analysis.

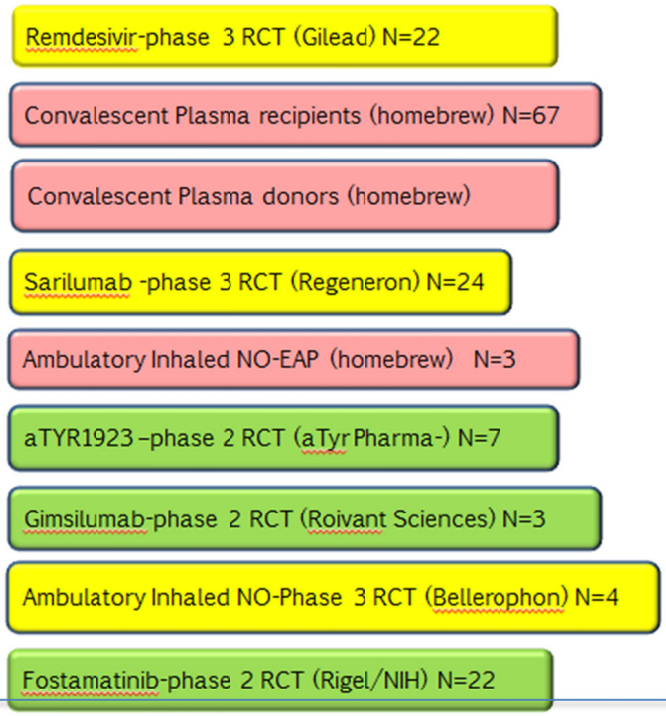
3. Biobanking. We have started an Inova COVID biobank and have collected more than 1,000 COVID samples thus far. We have collaborated with investigators at the NIH and George Mason University to make these samples available. We are hopeful that this will result in some exciting discovery work as we try to unravel the mysteries of this pesky virus.

4. NIH collaboration. We have always enjoyed a close relationship with intramural NHLBI. This only got tighter with the virus. We now Zoom weekly as we set out to "marry" our patient samples with the NIH's unique research capabilities. In addition, we have embarked on an exciting two center phase 2 trial with the NIH of a drug, fostamatinib, which shows promise as a COVID therapeutic.

5. Drug repurposing with George Mason University. At the outset of the pandemic, we were quick to establish a collaboration with Dr. Aarthi Narayanan, a Virologist at GMU, who has one of the few BSL-3 labs in the country to have the SARS CoV-2 virus. I can say that "I bought drugs over the internet" that were sent to Dr. Narayanan's lab to be tested against the virus. Not illicit drugs mind you, but commonly available compounds that potentially could be repurposed against SARS CoV-2. The work that Aarthi did in the lab with her post-grads is a prepress that is pending publication.

As we hopefully get back on track in 2021, we will continue to offer a broad array of potential research opportunities to our patients. We firmly believe that having the opportunity to be involved, while in most cases is altruistic, it is also empowering and an outlet to take a measure of control and **help "fight back"** against the disease. With any of our studies it is important to remember that your participation will not cost you anything and that the study drugs are paid for by the various pharmaceutical companies. The testing performed in the studies is also paid for unless it is deemed to be a part of your standard of care (testing you would have required anyway) in which case your insurance company will be billed.

Below is a flow diagram reflecting the spectrum and diversity of our COVID-19 treatment trials.



Publications and presentations (see below for full list).

We continue to be very active in research with COVID now added to the spectrum of diseases. In 2020 we had a record 23 original research manuscripts (accepted or published+2 preprints published), 4 reviews, 4 editorials, 3 case reports, and 5 book chapters. In addition, we had 53 presentations at International meetings this year, including the ATS, ISHLT, ERS, CFF and Chest 2020 meetings (all virtual). (With apologies for all these acronyms ☺)
It is a privilege to share our work with others and know that our research impacts the care of patients we never touch or see. We couldn't do research or writings without our patients, so please know that your participation in research has the same ripple effect on other patients around the country and around the world! That's pretty powerful stuff!

Website

We are always looking to update our website. Any new ideas for our website would be more than welcome. We are always looking for good patient stories to include on our website, so if you feel so inclined to share your story, please email it to me. Photos are also always a nice touch. Check us out at: www.inovalung.org

Inova Foundation Lung Funds.

Another way to fight back in support of our research is through contributions to one of our Foundation research funds. Four funds to consider contributing to include:

1) **The Lung Fund.** This is our broad generic fund, which we use for multiple purposes, including funding our research into all the diseases, including pulmonary hypertension, lung transplantation, sarcoidosis, cystic fibrosis, COPD and also IPF. We also rely on these funds to pay our research assistant as well as for statistical support, which is essential for our original research manuscripts (see below). We do tap into it on occasion to enable our personnel to attend educational conferences as well. While the hospital has set up an Emergency Research Fund to tap into for COVID-related projects, not all COVID-related research will qualify as an "emergency." Therefore, we will likely tap into this fund as well for some of our future COVID-related research.
2) **The Pulmonary Fibrosis Fund**. This fund remains open to receive donations from folks who wish to designate money specifically for pulmonary fibrosis research (including mostly, but not limited to IPF). What we are seeing as well in some of the COVID "long haulers" is that many patients are left with residual lung scarring (fibrosis). This is an emerging area that is ripe for research. We will therefore likely tap into this fund to support some of our research efforts in this area.

3) **Patient Assistance Fund.** We are into the 6th year of this fund, whose purpose is to help patients who are financially strapped. It is not for direct medical expenses but is tapped for other expenses related to traveling to our hospital for medical care. This includes things such as gas cards, food vouchers and accommodations, etc. If you wish to contribute specifically for this cause, then please designate so but still address it to "The Lung Fund," since it has been set-up as a subsidiary of the Lung Fund.
4) **Cystic Fibrosis Nutritional Support Grant.** Started by one of our generous CF patients and her family. This fund provides snacks and supplements in clinic as well as groceries to support those who have food insecurity at home. Please contact Dr. Brown or katie.coyle@inova.org if you're interested in donating.

We are extremely grateful to all who were kind and generous enough to donate to our Lung Fund in 2020. We realize that times are tough during the COVID pandemic, but if you do see fit to make a donation, please address to either "The Lung Fund," The Lung Fund-patient assistance" or the "The Pulmonary Fibrosis Fund" and send to:

c/o Debbie Campbell,
Heart and Lung Outpatient Area
Inova Heart and Vascular Institute,
3300 Gallows Road, Falls Church, VA 22042.

Thanks for reading all the way through! Once again wishing you a happy, healthy and medically boring 2021.

Steve Nathan
Medical Director, Advanced Lung Disease and Transplant Program

2020: the pictures do a story tell





WATITUDE
NATIONALS PARK
PNC
The Washington Post
Budweiser
THIS BUD'S FOR YOU.
DR. STEVEN NATHAN
AND DR. VIK KHANGOORA
INOVA HEALTH SYSTEM
Coca-Cola
ALL STAR GAME
HEALTHCARE APPRECIATION DAY


BIRTH PLACE: EARTH
RACE: HUMAN
POLITICS: FREEDOM
RELIGION: LIFE


CORONAVIRUS PANDEMIC
USING PLASMA DONATIONS TO FIGHT COVID-19
NATIONAL

Inova Advanced Lung Disease and Transplant Team
Group Zoom picture 2020:
A zoompic…and a sign of the times!
Inova Lung Transplant and Advanced Lung Disease Team Members (December 2020)

Top Row: Astrid "Julieth" Munoz (Program Manager); Vik Khangoora MD (Transplant Pulmonologist); Alicia Echols (PH Nurse Coordinator); Adriana Kochi (Quality Manager); Johanna Coughlin (PH Coordinator) ; Patricia Jackson (Pre-transplant Nurse Coordinator)

Second row: Michele Schreffler (Lead Nurse Coordinator) and Jessica Chun (Post transplant NP); Anju Singhal, MD (Advanced Lung Disease Fellow); Dana Prasanna (Transplant Quality Coordinator); Kareem Ahmad, MD (Transplant Pulmonologist); Morgan Wahl (Nurse Coordinator); Rebecca Packer (Nurse Coordinator);

Third Row: Lauren Cantwell NP (Clinical Manager); Adam Cochrane (Transplant Pharmacist); Melissa Bowen (CF Coordinator); Nikki Sisserson, PA; Elizabeth Davies (Social Worker); Steven Nathan, MD (Medical Director);

Fourth Row: Meg Fregoso (Nurse Practitioner); Shanna Guzman (PH Nurse Coordinator); Oksana Shlobin MD (Transplant Pulmonologist, Med Director PH Program); Shambhu Aryal, MD (Transplant Pulmonologist); Dan Tang (Surgical Director); A. Whitney Brown, MD (Transplant Pulmonologist, Med Director, CF Program);

Bottom Row: Lauren Marinak, (Inpatient Transplant NP); Chris King MD, (Transplant Pulmonologist, Med Director ALD &Transplant Critical Care); Susan Perry (Social Worker); Edwinia Battle (Research Manager);

Missing in action:

Administration: *Debbie Campbell (Transplant Director); Sarah Scott (Office Manager); Deanna Ridgeway (Financial Manager); Tameka Bland (Financial Specialist); Lori Hill (Financial Coordinator); Carlos Coronel (Sr. Admin Coordinator); Rosa Fuentes (Referral Coordinator); Stephanie Vargas (Referral Coordinator); Monserrat Cardenas (Referral Coordinator); Min Ahn (Practice Manager); Susie Rivero (Sr. Admin Coordinator,*

Research: *Vijaya Dandamudi (Clinic Research Regulatory Specialist); Martha Alemayehu (Clinical Research Nurse); Priscilla Dauphin (Research Coordinator); A. Claire Collins (Research Project Associate); Rebecca Hays (Clinical Research Nurse); Jennifer Pluhacek (Research Coordinator); Megan Harbor (Research Coordinator); Merte Lemma WoldeHanna (Research Coordinator); Yoel Sanchez Canales (Research project Associate)*

Docs: *Osman Malik, MD; Liam Ryan, MD; Eric Sarin, MD; Amit "Bobby" Mahajan, MD*

Ancillary Support*; Erin Lopynski (Dietician); Quyen Duong (CF RT)*

Academic Accomplishments 2020
(Inova authors bolded)

Original Research Manuscripts (accepted or published)

1. Min J, Badesch D, Chakinala M, Elwing J, Frantz R, Horn E, Klinger J, Lammi M, Mazimba S, Sager J, **Shlobin OA,** Simon M, Thenappan T, Grinnan D, Ventetuolo C, Al-Naamani N, on behalf of the PHAR Investigators. Prediction of health-related quality of life and hospitalization pulmonary arterial hypertension. Accepted to AJRCCM 11/20.
2. Borgese M, Badesch D, Bull T, Chakinala M, De Marco T, Feldman J, Ford JH, Grinnan D, Klinger J, Bolivar L, **Shlobin OA,** Frant R, Sager R, Sager J, Mathai S, Kawut S, Leary P, Gray M, Ropat R, Zamanian R. EmPHasis-10 as a measure of health-related quality of life in pulmonary arterial hypertension. Accepted to ERJ 10/20.
3. Min J, Feng R, Badesch D, Berman-Rosenzweig E, Burger C, Chakinala M, De Marco T, Feldman J, Hemnes A, Horn E, Lammi M, Mathai S, McConnell JW, Presberg K, Robinson J, Sager J, **Shlobin OA,** Simon M, Thenappan T, Ventetuolo C, Nadine Al-Naamani N, on behalf of the PHAR Investigators. Obesity in pulmonary arterial hypertension (PAH): The Pulmonary Hypertension Association Registry (PHAR). Accepted by Annals of the American Thoracic Society 10/20.
4. Kolaitis N, Zamanian R, De Jesus Perez V, Badesch D, Benza R, Burger C, Chakinala M, Elwing J, Feldman J, Lammi M, Mathai S, McConnell J, Presberg K, Robinson J, Sager J, **Shlobin OA,** Simon M, Kawut S, Glidden D, Singer J, De Marco T. Clinical differences and outcomes between methamphetamine-associated and idiopathic PAH in the Pulmonary Hypertension Association Registry. Accepted by Annals of ATS 10/20.
5. **King C,** Freiheit, E**, Brown AW, Shlobin OA, Aryal S, Ahmad K, Khangoora V,** Flaherty K, **Venuto D, Nathan SD**. Effects of Anticoagulation on Survival in Interstitial Lung Disease: An Analysis of the Pulmonary Fibrosis Foundation (PFF) Registry. Accepted by Chest October 11th 2020
6. **Nathan SD**, Flaherty K, Glassberg MK, Raghu G, Swigris J, Alvarez R, Ettinger N, , J. Loyd, P. Fernandes8, H. Gillies, P. Shah, M. Dekker, L. Lancaster. A Randomized, double-blind, placebo-controlled study to assess the safety and efficacy of pulsed, inhaled nitric oxide (iNO) at a dose of 30 mcg/kg-IBW/hr (iNO 30) in subjects at risk of Pulmonary Hypertension associated with Pulmonary Fibrosis (PH-PF) receiving Oxygen Therapy. Chest. 2020 158:637-645
7. Zhang M, Haughey M, Blease K, Couto S, Belka I, Hoey T, Groza M, Drew C, Hartke J, Bennett B, Cain J, Gurney A, Lachowicz J, Carayannopoulos L, **Nathan S**, Distler J, Brenner D, Hariharan K, Cho H, Xie W. Targeting the Wnt pathway through R-spondin 3 identifies an anti-fibrosis treatment strategy for multiple organs. PLoS One. 2020 Mar 11;15(3):e0229445. doi: 10.1371/journal.pone.0229445. eCollection 2020
8. **Shlobin OA**, Kouranos V, Barnett S, Alhamad EH, Culver DA, Barney J, Cordova FC, Carmona EM, Scholand MB, Wijsenbeek M, Ganesh S, Birring SB, O'Hare L, Baran JM, Cal JG, Lower EE, Engel PJ, Wells AU, **Nathan SD,** Baughman RP. Survival of Patients with Sarcoidosis Associated Pulmonary Hypertension: Physiological Predictors of Survival in Patients with Sarcoidosis Associated Pulmonary Hypertension: Results from a Multi-National Registry Cohort. Eur Respir J 2020; 55: 1901747 [https://doi.org/10.1183/13993003.01747-2019].
9. Alqawba M,, Rodriguez LR, Beuschel RT, Kaler M, Barochia AV, Levine SJ, **Nathan SD**, Grant G, Diawara N. Classification Models of Idiopathic Pulmonary Fibrosis Patients. Accepted to International Journal of Respiratory and Pulmonary Medicine 03/24/2020
10. **Nathan SD,** Yang M, Morgenthein EA, Stauffer JL. Forced Vital Capacity in Patients With Idiopathic Pulmonary Fibrosis: FVC variability in patients with IPF and role of 6-min walk test to predict further change. Eur Respir J 2020; 55: 1902151 (https://doi.org/10.1183/13993003.02151-2019)
11. Franck Rahaghi; Zeenat Safdar; **Anne Whitney Brown**; Joao A. de Andrade; Kevin R. Flaherty; Robert J. Kaner; **Christopher S. King**; Maria L. Padilla; Imre Noth; Mary Beth Scholand; Adrien Shifren; **Steven D. Nathan**. Expert consensus on the management of adverse events and prescribing practices associated with the treatment of patients taking pirfenidone for idiopathic pulmonary fibrosis: A Delphi consensus study. BMC Pulmonary Medicine (2020) 20:191 https://doi.org/10.1186/s12890-020-01209-4
12. **Nathan SD; Brown AW**; Nesrin Mogulkoc; **Soares F; Collins AC; Cheng JM; Peterson J; Cannon B; Barnett SD**, The White Blood Cell Count as a Prognostic Indicator in Idiopathic Pulmonary Fibrosis. Accepted to Res Med June 15, 2020
13. Raghu G, Colby TV, Myers JL, Steele MP, Benzaquen S, Calero K, Case AH, Criner GJ, **Nathan SD**, Rai NS, Hagmeyer L, Davis JR, Bhorade SM, Kennedy GC, Gauher UA, Martinez FJ. A Molecular Classifier that identifies Usual Interstitial Pneumonia in

Transbronchial Biopsy Specimens of Patients with Interstitial Lung Disease. Chest. 2020 May;157(5):1391-1392. doi: 10.1016/j.chest.2019.10.061.

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15. Luca Richeldi, Mary Beth Scholand, David A Lynch, Thomas V Colby, Jeffrey L Myers, Steve D Groshong, Jonathan H Chung, Sadia Benzaquen, **Steven D Nathan**, J Russell Davis, Shelley L Schmidt, Lars Hagmeyer, David Sonetti, Jurgen Hetzel, Gerard J Criner, Amy H Case, Murali Ramaswamy, Karel Calero, Umair A Gauhar, Yoonha Choi, Daniel G Pankratz, P Sean Walsh, Lori R Lofaro, Jing Huang, Sangeeta M. Bhorade, Gulia C Kennedy, Fernando Martinez, Ganesh Raghu. Utility of a molecular classifier as a complement to HRCT in identifying Usual Interstitial Pneumonia. Am J Respir Crit Care Med. 2020 Jul 28. doi: 10.1164/rccm 202003-0877OC. Online ahead of print.PMID: 32721166
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17. Behr J, **Nathan SD,** Wuyts WA, Mogulkoc Bishop N, Bouros DE, Antoniou K, Guiot J, Kramer MR, Kirchgaessler K, Bengus M, Gilberg F, Perjesi A, Harari S, Wells AU. Efficacy and safety of sildenafil added to pirfenidone in patients with advanced idiopathic pulmonary fibrosis and risk of pulmonary hypertension. Lancet Respir Med 2020 Published Online August 18, 2020 https://doi.org/10.1016/ S2213-2600(20)30356-8
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23. Aaron Waxman, MD, PhD, Ricardo Restrepo, MD,b Thenappan Thenappan, MD, Ashwin Ravichandran, MD, Peter Engel, MD, Abubakr Bajwa, MD, Roblee Allen, MD, Jeremy Feldman, MD, Rahul Argula, MD, Peter Smith, PharmD, Kristan Rollins, PharmD, CQ Deng, MD, PhD, Leigh Peterson, PhD, Heidi Bell, MD, Victor Tapson, MD, and **Steven D. Nathan, MD**. Inhaled Treprostinil in Patients with Pulmonary Hypertension due to Interstitial Lung Disease. Accepted N Engl J Med 10/23/2020.
24. **Christopher S. King, Dhwani Sahjwani, A. Whitney Brown, Saad Feroz,Paula Cameron, Erik Osborn, Mehul Desai,Svetolik Djurkovic, Aditya Kasarabada,Rachel Hinerman, James Lantry, Alan Speir, Oksana A. Shlobin, Kareem Ahmad, Vikramjit Khangoora, Shambhu Aryal, A. Claire Collins, Steven Nathan.** Outcomes of Mechanically Ventilated Patients with COVID-19 Associated Respiratory Failure. PLoS ONE 15(11):e0242651. https://doi.org/10.1371/journal.pone.0242651
25. **Jean Pastre; Scott D Barnett; Inga Ksovreli; Jeannie Taylor; A. Whitney Brown; Oksana A. Shlobin; Kareem Ahmad; Vikramjit Khangoora; Shambhu Aryal; Christopher S. King; Steven D. Nathan.** Idiopathic pulmonary fibrosis patients with severe physiologic deficit: characteristics and outcomes. Accepted Res Research Nov 16th 2020

Reviews

1. **King CK, Shlobin OA**. The Trouble with Group 3 Pulmonary Hypertension in Interstitial Lung Disease: Dilemmas in Diagnosis and the Conundrum of Treatment. Chest. 2020 May 7:S0012-3692(20)30872-2. doi: 10.1016/j.chest.2020.04.046.
2. **Shambhu Aryal, Christopher S. King.** Critical care of patients with pulmonary arterial hypertension. Curr Opin Pulm Med 2020, 26:414–421
3. **Vikramjit S. Khangoora, Oksana A. Shlobin**. Evolving spectrum of treatment for CTEPH. Curr Opin Pulm Med 2020, 26:406–413
4. **Steven D. Nathan**, Jack Wanger, Joseph D. Zibrak, Mark L. Wencel, Cindy Burg, John L. Stauffer. Using Forced Vital Capacity to Monitor Patients With Idiopathic Pulmonary Fibrosis in the Clinic: Pros and Cons. Expert Rev Respir Med. 2020 Sep 28:1-7. doi: 10.1080/17476348.2020.1816831.
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Editorials

1. **Aryal S, Nathan SD.** Lung Transplantation in China: a firm foundation for a solid future. Ann Transl Med 2020;8:41.
2. **Nathan SD.** POINT: Should every patient with IPF be referred for transplant evaluation? Yes. Chest. 2020 Jun;157(6):1411-1412. doi: 10.1016/j.chest.2019.12.033.
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3. **King CS.** A New Way Of Looking At An Old Problem. Chest. 2020 https://doi.org/10.1016/j.chest.2020.02.053
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Letters

1. Raghu G, Colby T, Myers J, Steele M, Benzaquen, Sadia ; Calero, Karel; Case, Amy; Criner, Gerard; **Nathan, Steven**; Rai, Navdeep; Hagmeyer, Lars; Davis, John; Bhorade, Sangeeta; kennedy, giulia; Gauhar, Umair; Martinez F. A molecular classifier that identifies usual interstitial pneumonia in transbronchial biopsies of patients with ILD. Accepted to Chest 10/4/2019

Book Chapters and Books

1. Chronic Thromboembolic Pulmonary Hypertension **Vik Khangoora,Oksana Shlobin;**for Current Opinions in Pulmonary Medicine. Interstitial Lung Diseases 2020. **Nathan SD**, **King C.**
2. Critical Care of Patients with Pulmonary Arterial Hypertension **Shambhu Aryal, MD, FCCP; Christopher S King, MD, FCCP** for Current Opinions in Pulmonary Medicine. Interstitial Lung Diseases 2020 .**Nathan SD**, **King C.**
3. **Shambhu Aryal, Vikramjit Khangoora, Steven D Nathan**. Lung Transplantation For Pulmonary Hypertension. For Encyclopedia of Respiratory Medicine
4. Current Opinions in Pulmonary Medicine. Interstitial Lung Diseases 2020 .**Nathan SD**, King C. Co- editors.
5. **Aryal S, Ahmad K, Nathan SD.** Group 3 PH: Clinical Features and Treatment: For Encyclopedia of Respiratory Medicine, 2nd Edition Medicine being published by Elsevier. https://doi.org/10.1016/B978-0-12-801238-3.11655-1

Case Reports

1. Mabe D, **Shlobin O, Bogar L**, **Nathan S, Brown A, Ahmad K, Aryal S,** Murphy C, **King C**. Extracorporeal Membrane Oxygenation as a Bridge to Initial Medical Therapy in a Patient With Decompensated Pulmonary Arterial Hypertension Presenting With Biventricular Failure. **Journal of Medical Cases**, North America, 10, Sep. 2019.
2. **Koslow M**, Bennji SM, Griffiths-Richards S, Ahmad K, Johnson GB, Ryu JH, **Nathan SD,** Allwood BW. A 48-year-old South African Woman with Rheumatoid Arthritis and Lung Nodules. Chest 2020;157:e151-e155
3. **Shalika Katugaha, Oksana Shlobin, Chris King, Steve Nathan, Shambu Aryal, Kareem Ahmad, Whitney Brown.** Donor Derived Strongyloidiasis: Life Cycle to Hyperinfection Syndrome. OBM Transplantation https://www.lidsen.com/journals/transplantation,ISSN2577-5820

ORIGINAL RESEARCH ABSTRACTS & PRESENTATIONS TO INTERNATIONAL MEETINGS

NACFC 2020

Gibson K, **Brown AW,** Lopynski E; **Davies-Wellborn E, King C,** Kahr M, Phillips Morrison ML, Riedy C, Standley J, Bush G, Blake S. Patient-centered Care of Hospitalized Adults with Cystic Fibrosis – a Collaboration Between the CF Care Team and the Patient Family Advisory Board. Accepted to NACFC
2020 (poster presentation).

Phillips Morrison ML, Reidy C, Kahr M, Jonathan Standley J, **Davies-Wellborn E,** Gibson K, **Brown AW**. Patient and Family Advisory Board (PFAB) Driven Clinical and Patient Driven Education. Accepted to NACFC 2020 (poster presentation).

Pulmonary Vascular Research Institute Meeting 2020

R.Alvarez,R.Dudenhofer,**K.Ahmad**,M.Glassberg,L.Lancaster,G.Raghu,J.Stewart,P.Fernandes,H.Gillies,P Shah,R.Baughman,**S.D.Nathan.** The Effects of Escalating Doses of PulsediNO on Pulmonary Arterial Compliance (PAC) Measured by Right Heart catheterization (RHC) in Patients with Pulmonary Hypertension (PH) associated with Pulmonary Fibrosis (PF). PVRI meeting Lima, Peru Feb 2020

International Society for Heart and Lung Transplantation 2020

1. Lung Transplant Recipients with Severe Primary Graft Dysfunction Requiring ECMO Had Similar Donor-Derived Cell-Free DNA Levels and Lung Function As Matched Controls. Submitted to ISHLT
2. Allograft injury and outcomes in minority race lung transplant recipients. Submitted to ISHLT
3. Severe Primary Graft Failure In Lung Recipients That Required ECMO Had Similar Donor-Derived Cell-Free DNA and Lung Function with Matched Controls. Submitted to ISHLT
4. **Ahmad K, King CK, Aryal S, Shlobin OA, Nathan SD, Katugaha S, Zorrilla S, Popa S, Marinak L, Ryan L, Brown AW.** Staged Bilateral Pneumonectomy: A Bridge to Lung Transplantation. To be submitted to the ISHLT 2020 Accepted
5. Severe Primary Graft Failure In Lung Recipients That Required ECMO Had Similar Donor-Derived Cell-Free DNA and Lung Function with Matched Controls. Accepted
6. Agbor-Enoh S, Ponor I, Levine D, Cochrane A, Philogene M, Shah P, Matthews J**, Brown AW**, Timofte I, Fideli U, Kong H, Marishta A, Bhatti K,Yang Y, Tunc I, Liukart H, Berry G , Marboe C, Iacono A , **Nathan SD**, Khush K, Orens J, Jang MK, Valantine HA. To treat or Not to Treat: DSA Positive Lung Transplant Recipients. Accepted
7. Agbor-Enoh S, Charya A, Jang MK, Luikart H, Shah P, Matthews J, **Brown AW**, Timofte I, Fideli US, Kong H, Marishta A, Bhatti K, Yang Y, Tunc I, Berry G, Marboe C, Iacono A, **Nathan SD**, Khush K, Orens J, Valantine HA. Allograft injury and outcomes in minority race lung transplant recipients. Accepted
8. Bazemore K, Permalung N, Shah P, Rohly M, Timofte I, **Brown AW,** Orens J, Iacono A, **Nathan S**, Avery R, Valantine H, Agbor-Enoh S, Shah P. Characterization of Respiratory Pathogens in Contemporary Lung Transplant Recipients. Accepted to ISHLT
9. Candida parapsilosis case report. Accepted

American Thoracic Society 2020

1. Behr J, **Nathan SD**, Harari S, Wuyts W, Mogulkoç N, Bouros DE, Antoniou K, Guiot J, Kramer M, Kirchgaessler KU, Bengus M, Gilberg F, Perjesi A, Wells AU. Efficacy and Safety of Sildenafil Added to Pirfenidone in Patients With Advanced Idiopathic Pulmonary Fibrosis (IPF) and Risk of Pulmonary Hypertension (PH). Submitted to ATS 2020
2. **Nathan SD**, Costabel U, Lancaster LH, Corte TJ, Nunes H, Schinzel B, Busquets JF, Quaresma M, Wells AU. Disease progression events in trials of nintedanib in patients with idiopathic pulmonary fibrosis. Accepted to ATS 2020 (poster)
3. D. M. Figueroa, O. Kalchiem-Dekel, W. Karkowsky, P. Theard, X. Yao, L. Rodriguez, S. Bui, G. M. Grant, **S. D. Nathan**, S. J. Levine. Apolipoprotein E Suppresses Collagen Expression in IPF Lung Fibroblasts by a MicroRNA-dependent Mechanism. To be submitted to ATS 2020
4. **Pastre J.; Ksovresli I.; Taylor J; King CS; Vik K; Oksana Shlobin; A.Whitney Brown; Kareem Ahmad; Shambhu Aryal; Nathan SD.** Antifibrotic therapy in IPF patients with severe physiologic impairment. Accepted to ATS 2020 (rapid abstract poster)

5. **Pastre J, Inga K, Taylor J, Brown AW, Khangoora V; Ahmad K, King CS, Nathan SD.** Idiopathic pulmonary fibrosis patients with severe physiologic deficits: characteristics and outcomes. Accepted to ATS 2020 (poster discussion)
6. **Pastre J, Inga K, Taylor J, Brown AW, Aryal S, King CS, Nathan SD.** IPF clinical trial PFT entry criteria: How low can we go? Accepted to ATS 2020 (poster)
7. **Jean Pastre; Scott Barnett; Inga Ksovreli; A. Whitney Brown; Oksana A. Shlobin; Kareem Ahmad; Shambhu Aryal, Vikramjit Khangoora; Christopher King; Steven D. Nathan**. Development And Validation Of A Clinical Diagnostic Score System For The Diagnosis Of IPF In Patients With Interstitial Lung Disease. Accepted to ATS 202 (poster discussion)
8. **Steven D. Nathan; Inga Ksovreli; Scott Barnett; Christopher King; Jean Pastre; Shambhu Aryal; Kareem Ahmad**; Cesar Fukuda; Vijaya Ramalingam; Jonathan Chung, MD.HRCT interpretation in patients with ILD: out with the old, in with the new and who changes categories. Accepted to ATS 2020 (poster)
9. **S. D. Nathan**, H. W. Farber, M. M. Chakinala, R. P. Frantz, A. E. Frost, S. Milligan, R. J. Oudiz; The Trio Pulmonary Arterial Hypertension Registry; A Platform Combining EMR Clinical Measures With Pharmacy Prescription And Dispensing Data. Accepted to ATS 2020 (poster)
10. **S. D. Nathan**, M. M. Chakinala, R. P. Frantz, A. E. Frost, S. Milligan, R. J. Oudiz, B. Weil, H. W. Farber; Do Prescribing Data Reflect Actual Treatment For Pulmonary Hypertension. Accepted to ATS 2020 (poster discussion)
11. **S. D. Nathan**, M. M. Chakinala, R. P. Frantz, A. E. Frost, L. Lancaster, K. Milligan, S. Milligan6, R. J. Oudiz, H. W. Farber;A Platform To Combine Clinical, Prescription, And Dispensing Data To Better Inform Idiopathic Pulmonary Fibrosis Care; The Trio Registry. Accepted to ATS 2020 (poster)
12. **Jessica McLaughlin, Osman Malik, A. Whitney Brown; Christopher King; Shambhu Aryal**. A Case Series of HeRO associated Thromboembolic Event
13. **Tora I, Aryal S**. A curious case of disappearing pulmonary fibrosis?
14. **V Kollipara, MD; S Katugaha, MD; W Brown, MD; C King.** Capnocytophaga sputigena: An Unusual Cause of Bronchiectasis Flare. Accepted ATS as a poster
15. **Elizabeth Gosciniak, Oksana A Shlobin, Christopher D King, Ramona Raya, Shambhu Aryal.** A Case of Steroid-Responsive Heart Failure in a Patient with Dermatomyositis
16. **Lauren Marinak, Kareem Ahmad; Jake Peterson, Christopher King; Shalika Katugaha; Amit Mahajan; A. Whitney Brown**. Endobronchial Valves for Persistent Bronchopleural Fistula after Pneumothorax in Cystic Fibrosis: A Double Edged Sword
17. R. A. Alvarez, R. Dudenhofer, **K. Ahmad**, M. K. Glassberg Csete, L. Lancaster, G. Raghu, J. I. Stewart, H. Gillies, P. Shah, R. P. Baughman, **S. D. Nathan**; An Acute Dose Escalation Study To Assess The Safety And Hemodynamic Efficacy Of Pulsed Inhaled Nitric Oxide (iNO) In Subjects With Pulmonary Hypertension Associated With Pulmonary Fibrosis (PF) Or Sarcoidosis. Submitted to ATS 2020.
18. Matthew Koslow, **Maria C. Albano, Scott D. Barnett, Kareem Ahmad, A. Whitney Brown, Shambhu Aryal,Christopher S. King, Oksana A. Shlobin, Brooks Culotta,Steven D. Nathan**. Non-Traumatic Vertebral Fractures are Associated with Decreased Survival in Lung Transplant Recipients. Accepted to ATS 2020 (poster discussion)
19. **Vikrajmit Khangarro, Husna Rahim, Alison Verster, Kareem Ahmad, Shambhu Aryal, A. Whitney Brown, Steven D. Nathan, Oksana A. Shlobin, Christopher S. King.** Pleural Effusions in Pulmonary Hypertension. Submitted to ATS 2020.
20. Rohit Gupta, Robert P. Baughman, **Steven D. Nathan**, Athol U. Wells, Vasilis Kouranos, Esam H. Alhamad, Daniel A. Culver, Joseph Barney, Eva M. Carmona, Marloes Huitema, Mary Beth Scholand, Marlies Wijsenbeek, Sivagini Ganesh, Surinder S. Birring, **Oksana A. Shlobin**. The Six-Minute Walk Test in Sarcoidosis Associated Pulmonary Hypertension: Results from an Ongoing International Registry. Submitted to ATS 2020
21. Lisa Lancaster, Ann Fieuw, Joyce Meulemans, Paul Ford, **Steven D. Nathan**. Standardization of the 6-Minute Walk Test in Idiopathic Pulmonary Fibrosis. Accepted to ATS 2020 (poster discussion)
22. **Melissa A. Bowen; Martha Alemayehu; Edwina Battle; A. Whitney Brown.** Promising Results with Elexacaftor/Ivacaftor/Tezacaftor Use in Cystic Fibrosis Patients with Advanced Lung Disease: Beyond the Clinical Trial Inclusion Criteria. Accepted to ATS 2020 (podium)
23. Andrei Minciunescu, Ivan F. Garcia, Eric A. Libre. Clinical Variations Associated with Vaping Product Use Associated Lung Injury. Submitted to ATS 2020
24. **S.D. Nathan**, K. Flaherty, M. K. Glassberg, G. Raghu, J. Swigris, R. Alvarez, N. Ettinger, J. Loyd, P. Fernandes, H. Gillies, P. Shah, L. Lancaster.A Randomized, double-blind, placebo-controlled study to assess the safety and efficacy of pulsed, inhaled nitric oxide

(iNO) in subjects at risk of Pulmonary Hypertension associated with Pulmonary Fibrosis (PH-PF) on Long Term Oxygen Therapy. Submitted as ate breaking abstract to ATS 2020

25. Jürgen Behr, **Steven D. Nathan**, Sergio Harari, Wim Wuyts, Nesrin Mogulkoç Bishop, Demosthenes E. Bouros, Katerina Antoniou, Julien Guiot, Mordechai Kramer, Klaus-Uwe Kirchgaessler, Monica Bengus, Frank Gilberg, Andras Perjesi, Athol U. Wells.Efficacy and Safety of Sildenafil Added to Pirfenidone in Patients with Advanced Idiopathic Pulmonary Fibrosis (IPF) and Risk of Pulmonary Hypertension (PH). To be submitted to ATS 2020 as late breaker.
26. McCormick A, Krishnan A, Badesch D, Benza RL, Bull T, De Marco T, Feldman J, Hemnes A, Hirsch R, Horn E, Kennedy J, Mathai S, McConnell JW, Pugliese SC, Sager JS, **Shlobin O,** Simon M , Lammi MR. Pulmonary artery compliance in pulmonary arterial hypertension and chronic thromboembolic pulmonary hypertension: The Pulmonary Hypertension Association Registry.
27. Min J, Feldman J, Sager J, **Shlobin O,** McConnell JW, Lammi M, Frantz R, Ventetuolo C, Klinger J, Zamanian R, Robinson J, Elwing J, Badesch D, Thenappan T, Simon M, Ryan J, Mazimba S, Grinnan D, Chakinala M, Horn E, Al-Naamani N. Risk Prediction Models Are Associated With Patient Centered Outcomes In PAH: The Pulmonary Hypertension Association Registry. American Thoracic Society International Conference, May 2020. (Poster presentation).
28. Narasimmal S, S. Pugliese, T. M. Bull, T. De Marco, J. W. McConnell, M. R. Lammi, T. Thenappan, J. P. Feldman, J. S. Sager, D. B. Badesch, J. J. Ryan, D. Grinnan, D. Zwicke, E. Horn, J. M. Elwing, J. Robinson, J. E. Moss, M. Eggert, **O. A. Shlobin,** R. P. Frantz, S. Bartolome, S. C. Mathai, S. Mazimba, N. Al-Naamani. Quality Of Life Of Patients With Chronic Thromboembolic Pulmonary Hypertension (CTEPH) And Idiopathic Pulmonary Arterial Hypertension (IPAH): The Pulmonary Hypertension Association Registry (PHAR)
29. Grinnan D, **Shlobin OA,** DeWilde C, Chakinala M, Ford J, Klinger J, Kawut S, Sager J, Zamanian R, Gray M, Benza R, Badesh D, Bull T, De marco T, Feldman J, Rozensweig E. Derivation of the PHA Registry Evaluation. Derivation Of The Pulmonary Hypertension Association Registry Evaluation (PHARE).
30. Gosciniak E, **Shlobin OA,** Raya R, **King CS, Aryal SA.** A Case Of Steroid Responsive Heart Failure In A Patient With Dermatomyositis.

European Respiratory Society 2020

1. Behr J, **Nathan SD**, Harari S, Wuyts WA, Kirchgaessler KU, Bengus M, Gilberg F, Wells AU. Outcomes from three RCTs of sildenafil with and without antifibrotics in advanced IPF. To be submitted to ERS 2020
2. Behr J, **Nathan SD**, Harari S, Wuyts W, Kirchgaessler K-U, Bengus M, Gilberg F, Wells AU.A comparison across right heart catheterisation (RHC) and NT-proBNP subgroups in a randomised placebo-controlled trial of sildenafil + pirfenidone in patients with advanced idiopathic pulmonary fibrosis (IPF) at risk of pulmonary hypertension (PH). To be submitted to ESC

American College of Chest Physicians 2020

1. Anthony Rowe, MD; Ankush Ratwani, MD; Scott Barnett, PhD; Christopher S. King, MD; Oksana Shlobin, MD; **Steven D. Nathan**, **MD**. A retrospective descriptive analysis of systemic sclerosis-related interstitial lung disease and pulmonary hypertension.
2. Aaron Waxman, Ricardo Restrepo-Jaramillo Thenappan Thenappan, Ashwin Ravichandran, Peter Smith, Erick Borg, Lisa Edwards, Victor Tapson, **Steven D. Nathan**. The Impact of Inhaled Treprostinil on Patient Lung Function – Results from the INCREASE Study.
3. Stevens A, **Shlobin O, King C, Khandhar S, Nathan SD**. Does Surgical Lung Biopsy Change Management in Hospitalized Patients with Suspected ILD?.
4. Stephen Humphries, Marla Johnson, **Steven Nathan**, Lori Lofaro, Dan Pankratz, Sangeeta Bhorade, Giulia Kennedy, Jing Huang, David Lynch. Relationship between Envisia Genomic Classifier (EGC) and an HRCT-derived fibrotic index from data-driven texture analysis (DTA) on 50 ILD patients.
5. V**. Khangoora, C. S. King, O. Shlobin, A. W. Brown, S. Aryal, K. Ahmad, S. Nathan**. Higher Donor PaO2/FiO2 Ratio Appears to Be Associated with Increased Incidence of Primary Graft Dysfunction in Lung Transplant Recipients. accepted to Chest 2020.
6. **Collins AC, King CS, Nathan SD**. Outcomes in patients with IPF and pulmonary hypertension.
7. Anusha Yelisetty, Vijaya Ramalingam**, Steven Nathan**. Ischemic colitis with Nintedanib use; the conundrum of a common symptom due to a rare cause.

8. Karim El-Kersh; **Christopher King**; Eric Shen; Peter Classi; Vijay P. Balasubramanian. Contemporary Dosing Characteristics of Oral Treprostinil in Real-world Clinical Practice in Patients with Pulmonary Arterial Hypertension

AMCP meeting 2020

David Singer, Misti L. Paudel, Sharash Shetty, Lisa Le, Craig Conoscenti, Steven D. Nathan. Clinical and Demographic Characteristics of Patients with Idiopathic Pulmonary Fibrosis who have Preserved Lung Function.

TEAM SHOTS 2019. I have included these same pictures from last year, since all team pics this year have been with masks!

PULMONARY HYPERTENSION TEAM

ADVANCED PRACTICE PROVIDERS

RESEARCH TEAM

DOCS

COVID-19 vaccine musings:

Below with her permission is Dr. Brown's personal account of receiving the COVID-19 vaccine that was shared on the Cystic Fibrosis Foundation blog.

Cystic Fibrosis Community Blog – my COVID-19 Vaccine Experience
Dr. A. Whitney Brown

As an adult CF doctor, I have seen the importance of participating in clinical trials firsthand. Certainly, after seeing the positive impact that Trikafta has had our on CF community, I am especially grateful to those who took at leap of faith and enrolled in the clinical trials that made it possible.

On a personal level, like many, by September 2020 I was growing weary of COVID-19 and of 2020 in general. I was motivated to get access to a potential COVID-19 vaccine as soon as possible, so when I heard that the infectious disease practice across from the hospital was a site for the Pfizer vaccine trial, I filled out the interest form right away. By the next business day, I was booked for my first study visit in 3 days' time. On September 3rd, I showed up for my first visit not knowing what to expect. I have been involved in clinical trials on the medical side, but never as a study participant myself. I figured they would consent me for the study and then do some basic tests to make sure I was eligible. I had no idea that I would get my first vaccine dose that day…so I didn't have time to over-think it or really even be nervous.

After checking my vital signs, they did a COVID-19 nasal PCR test, drew my blood, and then gave me the first dose of the vaccine. I was required to be observed for 30 minutes after the shot and then I went right back to work. As the day went on, I noticed my left upper arm hurt a little but admittedly, I have a skinny arm and I had flinched when they gave me the shot. That night, I woke up during the night with discomfort in my arm and took ibuprofen, which helped. I made note that I should probably ask for the next shot in my right (dominant) arm and avoid my left arm since I sleep on that side. And that was it. By the next night, the pain was gone.

Three weeks later, I went back for my second dose. By that time, I had read more about the vaccine design. I felt reassured that the mRNA vaccine does not contain any actual virus, but instead the messenger RNA (the code that instructs the body to make a protein) for the spike protein on the outside of the virus. Based on what I read in the phase 1 study, it seemed like about 85% of people who got the real vaccine (rather than the placebo) in the first study had side effects after the 2nd dose….so I figured that the second dose could be tougher. At that point, I couldn't have told you if I was getting the vaccine or the placebo based on my experience with the first dose. A sore arm could happen with any injection (saline placebo or medication), I thought. So I was a little bit nervous at my second visit on September 24th. On one hand, I was a little scared of the unknown and how I might feel after the shot. On the other hand, I really wanted to get the actual vaccine and I knew that side effects were a good sign of the body responding to the vaccine and building immunity.

At the second visit, they did another nasal swab and then gave me another shot. This time, I asked for it in my right arm having learned my lesson with the first dose. I took ibuprofen right after getting the vaccine and went back to work. That night, I took another dose of ibuprofen before bed and slept well. The next morning, I woke up with a mild headache and headed into the

hospital for CF Clinic. Around noon, I was starting to drag a little bit. I felt a chill, but no one else thought it was cold in clinic. As the afternoon went on, I felt more tired and was relieved when clinic was over and I could go home. I decided to finish my charts another day. I couldn't wait to get into a hot bath to relax. My muscles felt sore and my neck was a little stiff. A bath, a cup of tea, and some ibuprofen helped a lot. I went to bed early that night and woke up during the night with a low grade fever of 100.5°F, which is very unusual for me as my temp usually runs on the low side. The next day was Saturday and fortunately, I didn't have to work. Other than getting up to get some breakfast, I listened to my body and stayed in bed and rested until 2pm. Around mid-afternoon, I felt better, got up and showered, and went to the grocery store. By the next morning, I felt essentially back to normal and did my normal Sunday morning yoga. Never did I feel any respiratory symptoms like cough or shortness of breath.

A week later, my husband, Rick, who was also enrolled in the vaccine study, had a similar experience, although milder. He felt more prepared for his second dose and knew what to expect based on what happened to me. He went to bed the night of his 2nd shot saying, "Bring it on!" He was hopeful to get a chance at immunity, too.

Because of the symptoms that we had, we were fairly sure that we had received the actual vaccine. Of course, we found out nothing through the study since it was blinded. Through a study on healthcare workers at the hospital, I found out that my COVID-19 antibody test was positive on October 2nd after being negative since the beginning of the pandemic…which was a good sign. But the real test came later in October when our live-in childcare provider (also enrolled in the study but never had any side effects with her shots so presumably got the placebo) came down with a cold. As part of the study, she was asked to do a nasal swab on herself. The swab was picked up by UPS that day and sent to the Pfizer study hub. Several days later, she was informed she had COVID-19. Amazingly, Rick and I didn't get sick (our daughters got cold-like symptoms) despite living under the same roof and having dinner with her every night. This was extremely reassuring and pretty compelling evidence that the vaccine works, especially since my husband usually picks up every infection that comes his way. We joked that our house was a microcosm of the Pfizer study. Rick and I dodged COVID-19 and, thankfully, our nanny and girls recovered quickly.

It has been a relief to have protection from the virus over the past few months, although I know better than to let down my guard. I consistently wear PPE and make safe decisions to minimize my exposure to the virus, but I don't worry about my family quite as much anymore. In mid-December, I found out officially from Pfizer that I received the vaccine, not placebo. Deeply grateful for the opportunity to be involved in making history and getting the vaccine approved, I would do it all again.

In a year characterized by total of lack of control, I see choosing to get the vaccine as taking control…control of when your body is exposed to COVID-19 (or the vaccine "fake-out"). As unpredictable as COVID-19 can be, a little predictability and planning is a welcome change. I would gladly take 1-2 days of feeling crappy to a wildly unpredictable and dangerous virus.
They say herd immunity is the only way we will move on from COVID-19, and I much prefer getting my immunity through the vaccine rather than the real deal. I am recommending that my patients do the same. People with CF are tough, and COVID-19 vaccination will likely be much easier than most CF flare-ups, and much shorter lived.
Choose wisely. Fight back against COVID-19. Take back control.

Some vaccine lessons learned:

- Expect the vaccine to have side effects (more with the second dose than the first).
- If or when you feel side effects, this is not COVID-19 – it is the "fake out" effect of the vaccine on your immune system.

Answers to the quiz on page 13

1. Vik Khangoora
2. A. Whitney Brown
3. Karɜem Ahmad
4. Jess Chun
5. Oksana Shlobin
6. Nikki Sisserson
7. Lauren Marinak
8. Shambhu Aryal

Final question: How many times was COVID mentioned in this newsletter?
Answer: 59

It's been a long year, hence a long newsletter, thanks for hanging in until the end!