



December 29th, 2023

Dear Colleague,

Seasons greetings! How quickly the year has gone by and before you know it, it's time for the Inova Advanced Lung Disease and Lung Transplant annual program update. So as not to disappoint, here goes...

Lung Transplant Volumes- another record year: 2023 was a landmark year for our lung transplant program with 50 lung transplants performed (with 2 days still to go 😊), besting our prior high of 42 lung transplants from last year. Of these there were 46 were bilateral lung transplants, 4 were heart-lung transplants (another record) and #50 was a bilateral lung-kidney transplant. Seven of these transplants were performed on patients who were on ECMO support (another record). We also listed a record 56 patients (versus 45 in 2022) for lung transplant this year. Our program has also now performed a total of 651 lung transplants to date.

Survival: Based on the most recent data from The Scientific Registry of Transplant Recipients (SRTR), our survival statistics remain favorable compared with the National averages. Our one-month survival is 98.53% (n=70) vs 97.54% for the national average (hazard ratio (HR)= 0.81); 1 year survival 87.01% vs 87.62% (HR 0.99) and adjusted 3 year survival 75.5% vs 76.0% (HR 1.17). Of course, all programs desire a 100% survival, but this is not feasible as we broaden our inclusion and narrow our exclusionary criteria. For example, we transplanted our first HIV+ patient this year and performed our first combined lung-kidney. We have now also increased our upper age limit to 75 years. We still talk about a "window of opportunity" for lung transplantation but have now extended the backend of the window; for example, with the use of ECMO as a bridge to transplantation. This inevitably results in "sicker" patients being transplanted which puts a bit of a lid on our one-year survival. An attestation to the acuity of our transplant recipients is that **43.6% of these folks are waiting in-house** (≈21% in the ICU). This compares to the National average of 29% in-house (SRTR data). For 2023, 34/50 transplants (**68%**) were of patients who were in the hospital waiting for their transplant. At the end of the day (or end of the year in this case), we are offering the option of lung transplantation to more patients and hopefully saving more lives as evidenced by our growing number of transplants.

New allocation system "CAS" effective March 2023: The new continuous allocation system seems to be working quite well with increasing donor calls and our ability to get pretty much all our listed patients transplanted in a timely fashion as evidenced by our median waiting time being reduced to **9 days** for in-house patients and 43 days for those waiting at home.

Advanced Lung Disease Program volumes: We evaluated over 600 new patients in 2023 and now follow a total of 2,169 patients with various forms of advanced lung disease. This represents 26.6% year to year growth compared with 2022. This was accompanied by a record number of clinic encounters (≈5,300) this past year. We continue to offer the advantage of an integrated program with patients seamlessly transitioning from one of our Advanced Lung Disease Programs to our Transplant Program. To accommodate our increasing volumes, we opened an additional ALD clinic out at Inova Loudoun Hospital in 2021. For more advanced therapies, such as IV prostanoids for PAH or transplant candidates/recipients, patients will still need to be seen at the mothership.

Comprehensive program update: As of December 2023, there were 63 CMS accredited adult lung transplant centers, 75 accredited Adult Comprehensive Care Centers for Pulmonary Hypertension, 81 Pulmonary Fibrosis Foundation Care Centers, 119 Cystic Fibrosis Foundation-accredited Care Centers and 33 WASOG (Sarcoidosis) Centers of Excellence in the United States. We are proudly one of **only 13 programs** in the Nation to hold all of these designations.

Personnel update: There have been no new personnel moves among our docs (phew!) Every year I provided a breakdown of our accrued experience which is as follows: Our 8 physicians have been with the Program a total of 89 years (SN-27; OS-18; AWB-13; CK-10, SA-7, VK-5, AS-4, AN-3, CT-2). Osman Malik also works with us part-time as a 0.2 FTE and June Chowdhury will be joining us as a part-time FTE in 2024. The remainder of Osman and June's time is spent with our Medical Critical Care Service. Shahzad Ahmad who was formerly with our program before moving to CA has moved back to our area and is helping out with weekend coverage 😊

Kudos and "skudos": Oksana Shlobin is chairing the 7th World Pulmonary Hypertension Symposium Group 3 Task Force in Barcelona in June 2024. Shambhu Aryal has been invited to be an associate editor for the Journal of Heart Lung Transplant Open. I was personally honored this year to be the annual CHEST 2023 College Medalist Award recipient which I received at the annual meeting in Honolulu. Forgive the self-kudo (aka a "skudo"), which is largely attributable to the wonderful nominating letter my colleagues crafted together.

Education: We had **43 Fellows and Residents** rotating through with us in 2023 and are currently in the 7th year of our Advanced Lung Disease and Transplant fellowship. This year

our Fellow is Dr. Jared Wilkinson who completed his Pulmonary and Critical Care at UCLA. We are hoping that Jared will be staying on with us as a full-time Attending. Our Fellow from last year Dr. Onix Cantres was highly sought after and took a lung transplant job with the lung transplant program in Orlando, FL..

Publications and presentations: This year marked another year of great academic productivity with 29 original research manuscripts published, and a further 7 accepted for publication or epub'ed. This is in addition to authorships on 4 consensus papers, 8 review papers, 2 letters, 33 abstracts, and 4 book chapters. You can find all our publications at the end of this letter. Also included is a publication highlights section of noteworthy publications that we believe are most relevant to our referring doc's clinical practice.

We continue to hold monthly program specific multidisciplinary meetings for multiple disease groups. These meetings include:

- ① **Pulmonary hypertension: 7:30-8:30 am EST on the 2nd Wednesday of the month**
- ② **ILD: 7:30-8:30 am EST on the 2nd Thursdays of the month.**
- ③ **CTEPH-: 7:00-8:00 am EST 3rd Wednesdays of the month**
- ④ **Sarcoidosis: 7:00-8:00 am EST 2nd Friday of the month.**

We invite all referring physicians to participate, available remotely via Teams, especially if you have any "tough" cases and wish to solicit input from our group. If interested, please contact us and we can share the meeting invitation/link with you.

We couldn't possibly provide the service we do without your support and ongoing co-management of our complex patients. We pride ourselves on our collaborative style, our close communication, and the relationships we enjoy and foster with our patients' primary Pulmonologists and other providers. Please feel free to call or email any of our docs with new referrals, questions, issues, or updates on existing patients (contact info next page). If any patients need to be seen expeditiously, then **please call or email one of us directly** and we will accommodate them earlier.

In summary, a lot of growth in 2023 including patients and pubs, all of which we are very proud. On behalf of our team, wishing you, your staff, and families a happy, healthy New Year. Thank you for your ongoing support and confidence in our Program.

With best wishes,

Steven D. Nathan
Steven Nathan, MD
Medical Director

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Advanced Lung Disease and Transplant Program Referrals

Advanced Lung Disease (including ILD, COPD, Sarcoidosis, A1AT, diagnostic dilemmas)

Stephanie Vargas; 703-776-7939 (tel);

stephanie.vargas@inova.org

ildreferrals@inova.org

Pulmonary Hypertension

Arti Sharma; 703-776-6168 (tel)

arti.sharma@inova.org

phreferrals@inova.org

Lung Transplant, Cystic Fibrosis and non-CF Bronchiectasis

Janah Bernabe; 703-776-7876 (tel)

Janah.Bernabe@inova.org

CFappointments@inova.org

ltxreferrals@inova.org

703-776-3515 (fax)

Alternatively: referrals can be emailed to

PHYSICIAN CONTACT INFORMATION

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jared.wilkinson@inova.org



Getting to know us section

I would like to take this opportunity to introduce two of our newest docs.

Dr. Osman Malik

Osman trained in Internal Medicine at University of Tennessee in Memphis and then went on to fellowship in Pulmonary and Critical Care at Baylor Medical College in Texas. In addition to Pulmonary and Critical Care, Osman is also boarded in Sleep Medicine and Neurocritical Care. After completing his training, Dr. Malik was in private practice in Kansas for 8 years before moving to Virginia in 2012 and joining the Inova Critical care section. After initially doing critical care only, Dr. Malik transitioned some of his time to our ALD clinic and has a special interest in ILD, pulmonary embolism and pre-transplant evaluations. His clinic and ICU roles have provided the opportunity for different perspectives in the care of our patient population. Dr. Malik particularly enjoys the long-term relationship that develops with ALD patients and the excellent collaboration within the ALD team with their different expertise. He is the main point person in our ALD clinic in Loudoun. Dr. Malik is married with 3 kids, the oldest is a senior now applying to college. He loves living in the diversity of the DMV area, taking family road trips throughout the East coast, and bicycling on the local trails.

Getting to know Jared Wilkinson

Jared made his way back to Inova following fellowship in pulmonary and critical care at UCLA. A native of the Midwest, he completed medical school at Washington University in St. Louis before moving on to residency at the University of Michigan (Go Blue!) where he met his wife, Sasha. Following residency, he spent several years as a hospitalist, including two years at Inova where he taught both the evidence-based medicine curriculum and point-of-care ultrasound course for the residency program. He's passionate about medical education having been twice voted faculty teaching attending of the year as a hospitalist here, as well as fellow of the year by the UCLA internal medicine residency program. While at UCLA he came to appreciate the multidisciplinary nature and complex needs of patients with ILD, pulmonary hypertension, and lung transplant. He's happy to be back in the DC area and thrilled to return to Inova. In his free time, he's an enthusiastic enophile, intrepid traveler, and ardent bibliophile.



Research and Publication highlights

It is very difficult to pick from all the manuscripts that one or more of us played a role in. Without diminishing the importance of any of the others, here are 4 that are arguably of most clinical relevance to our referring physicians (in no particular order 😊)

1. **Thomas C, Chandel A, King CS, Aryal S, Brown AW, Khangoora V, Nyquist A, Singhal A, Cantres Fonseca O, Shlobin O, Nathan SD.** Prevalence of pulmonary hypertension in patients with COVID-19 related lung disease listed for lung transplant: a UNOS Registry Analysis. *Pulm Circ.* 2023 Apr 1;13(2):e12228. doi: 10.1002/pul2.12228. eCollection 2023 Apr. PMID: 37091120

In keeping with our group's leadership role in group 3 PH, in this study we describe yet another cause of diffuse parenchymal lung disease as being associated with the development of pulmonary hypertension. No surprise COVID-ILD does it as well!

DOI: 10.1002/pul2.12228

RESEARCH ARTICLE

Pulmonary Circulation | PVRI | WILEY

Prevalence of pulmonary hypertension in patients with COVID-19 related lung disease listed for lung transplantation: A UNOS registry analysis

Christopher Thomas¹ | Abhimanyu Chandel² | Christopher S. King¹ | Shambhu Aryal¹ | A. Whitney Brown¹ | Vikramjit Khangoora¹ | Alan Nyquist¹ | Anju Singhal¹ | Onix Cantres Fonseca¹ | Oksana Shlobin¹ | Steven D. Nathan¹

2. **Nathan SD, Deng C, King CS, DuBrock HM, Elwing J, Rajagopal S, Rischard F, Sahay S, Broderick M, Shen E, Smith P, Tapson VF, Waxman AB.** Inhaled Treprostinil Dose in Pulmonary Hypertension Associated with Interstitial Lung Disease and Its Effects on Clinical Outcomes. *Chest* 2023;163:398-406

In this post-hoc analysis of the INCREASE trial, we demonstrate a nice dose-response to inhaled Treprostinil in patients with PH-ILD with more clinical improvement and less clinical worsening in those who achieve a dose >9 breaths four times a day.

[Pulmonary Vascular Original Research]

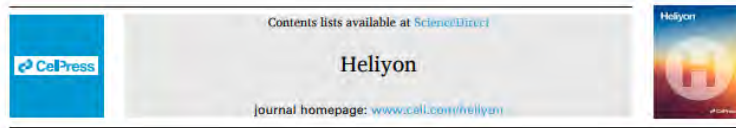
CHEST

Inhaled Treprostinil Dosage in Pulmonary Hypertension Associated With Interstitial Lung Disease and Its Effects on Clinical Outcomes

Steven D. Nathan, MD; Chunqin Deng, PhD; Christopher S. King, MD; Hilary M. DuBrock, MD; Jean Elwing, MD; Sudarshan Rajagopal, MD; Franz Rischard, MD; Sandeep Sahay, MD; Meredith Broderick, PharmD, JD; Eric Shen, PharmD; Peter Smith, PharmD; Victor F. Tapson, MD; and Aaron B. Waxman, MD, PhD

3. **Christopher S. King**, Emily White, Joshua Mooney, **Shambhu Aryal**, **Oksana A. Shlobin**, **Singhal**, **Christopher Thomas**, **Vikramjit Khangoora**, **Alan Nyquist**, Kevin Flaherty, **Steven D. Nathan**. Factors Associated with Listing for Lung Transplantation in IPF Patients: An Analysis of the Pulmonary Fibrosis Foundation Registry. *Heliyon*. 2023 Aug 5;9(8):e18618. doi: 10.1016/j.heliyon.2023.e18618. PMID: 37600402; PMCID: PMC10432603.

Bottom line- if they are of transplant age (<75 years) and have no absolute contraindications, please refer IPF patients as early as possible, even if asymptomatic.



Factors associated with listing for lung transplantation in IPF patients: An analysis of the pulmonary fibrosis foundation registry

Christopher S. King^a, Emily White^b, Shambhu Aryal^a, Oksana A. Shlobin^a, Anju Singhal^a, A. Whitney Brown^a, Christopher Thomas^a, Vikramjit Khangoora^a, Alan Nyquist^a, Kevin R. Flaherty^c, Steven D. Nathan^a, Joshua J. Mooney^d

^a Advanced Lung Disease and Transplant Program, Inova Fairfax Hospital, Falls Church, VA, USA


^b University of Michigan, Department of Biostatistics, USA

^c University of Michigan Division of Pulmonary & Critical Care Medicine, USA

^d Stanford University, Division of Pulmonary and Critical Care Medicine, USA

4. Michael B. Keller, Xin Tian, Deniz Ozisik, Moon Kyoo Jang, Rohan Meda, Ananth Charya, Gerald J. Berry, Charles C. Marboe, Hyesik Kong, Ileana L. Ponor, **Shambhu Aryal**, Jonathan B. Orens, Pali D. Shah, **Steven D. Nathan**, Sean Agbor-Enoh. Organizing pneumonia is associated with molecular allograft injury and the development of antibody-mediated rejection. *J Heart Lung Transplant*. 2023 Nov 14;S1053-2498(23)02125-3. doi: 10.1016/j.healun.2023.11.008. Online ahead of print. PMID: 37972825

We are proud to be a major contributor and founding member of the NIH-sponsored GRAFT consortium which is 10 years old in 2024. Output from the GRAFT consortium has really led the field in terms of the utility of donor-derived cell-free DNA as a clinical tool that is used by most lung transplant programs today.

FULL TEXT ARTICLE 

Organizing pneumonia is associated with molecular allograft injury and the development of antibody-mediated rejection  

Article in Press: Accepted Manuscript

Michael B. Keller MD, Xin Tian PhD, Moon Kyoo Jang PhD, Rohan Meda B.S., Ananth Charya MD, Deniz Ozisik, Gerald J. Berry MD, Charles C. Marboe MD, Hyesik Kong PhD, Ileana L. Ponor MD, MBA, Shambhu Aryal MD, Jonathan B. Orens MD, Pali D. Shah MD, Steven D. Nathan MD and Sean Agbor-Enoh MD, PhD

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Forthcoming attractions

Coming your way soon is the FORD index. This is a composite score based on non-invasive readily available clinical parameters to predict the presence of PH in patients with IPF. This paper is pending publication in the Journal of Heart Lung Transplant. I think our cover letter to the Editor helped the cause or at least got a chuckle, “*While our acronym (the FORD model) seems somewhat whimsical, we feel that this has “wheels” and hope that our paper can find a parking spot in your esteemed journal.*”

FULL TEXT ARTICLE

Derivation and validation of a non-invasive prediction tool to identify pulmonary hypertension in patients with IPF: evolution of the model FORD

Article in Press: Accepted Manuscript

Steven D. Nathan MD, Abhimanyu Chandei MD, Ya Wang Ph.D., Jiawei Xu Ph.D., Lixin Shao MD., Timothy R. Watkins MD, Jack Diviney MS, Christopher S. King MD and Ling Han MS

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A pending publication (currently an epub) in Thorax includes some fancy modelling (aka “statistical gymnastics”) where we looked at potential (improved) survival of patients with PH-ILD treated with inhaled treprostinil.

Interstitial lung disease



Original research

Survival analysis from the INCREASE study in PH-ILD: evaluating the impact of treatment crossover on overall mortality

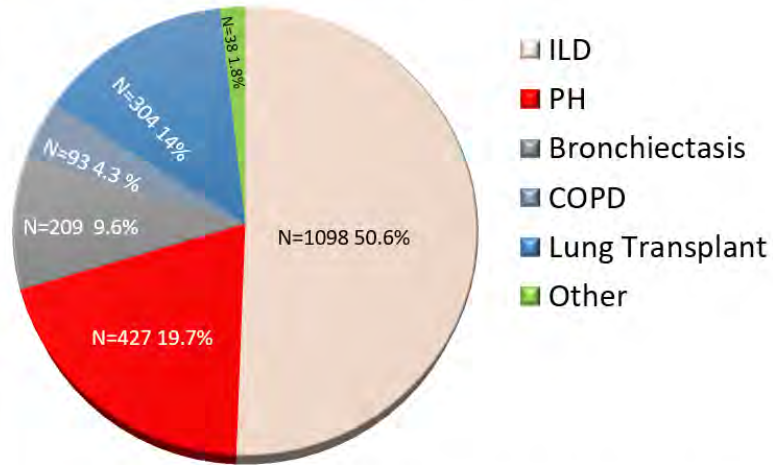
Steven D Nathan ,¹ Shilpa Johri,² Joanna M Joly,³ Christopher S King,¹ Amresh Raina,⁴ Colleen A McEvoy,⁵ Dasom Lee,⁶ Eric Shen,⁶ Peter Smith,⁶ Chunqin Deng,⁶ Aaron B Waxman⁷

BMJ

Nathan SD, et al. *Thorax* 2023;0:1–6. doi:10.1136/thorax-2023-220821

CLINIC DISEASE CATEGORIES:

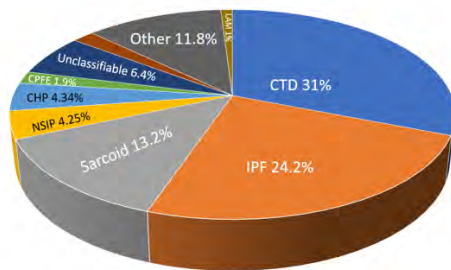
2023: Clinic patient groups (outpatients only)



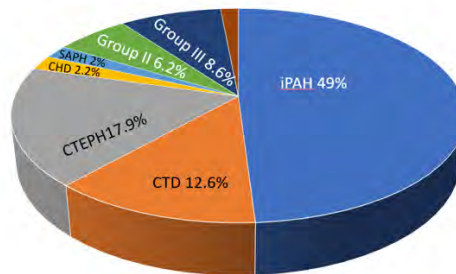
Total patients=2,169

Collated from November 2022-November 2023

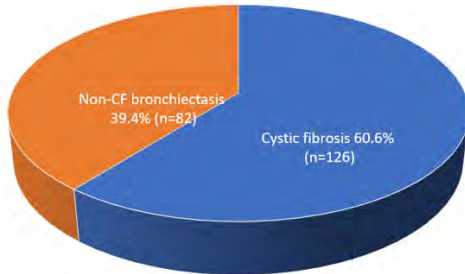
ILD subtypes 2023 (n=1098)



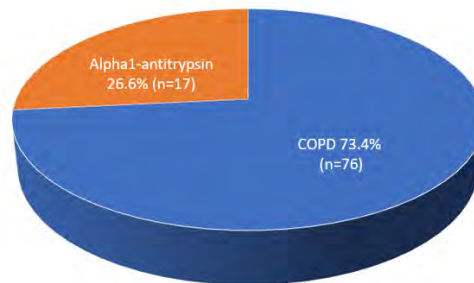
PH subtypes 2023 (n=427)



Bronchiectasis 2023 (n=208)

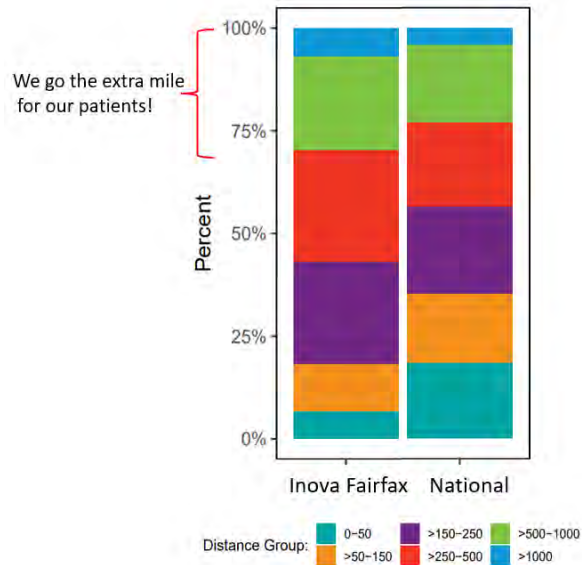


COPD 2023 (n=93)

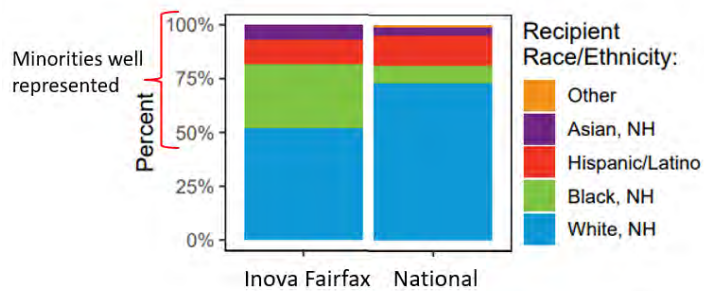
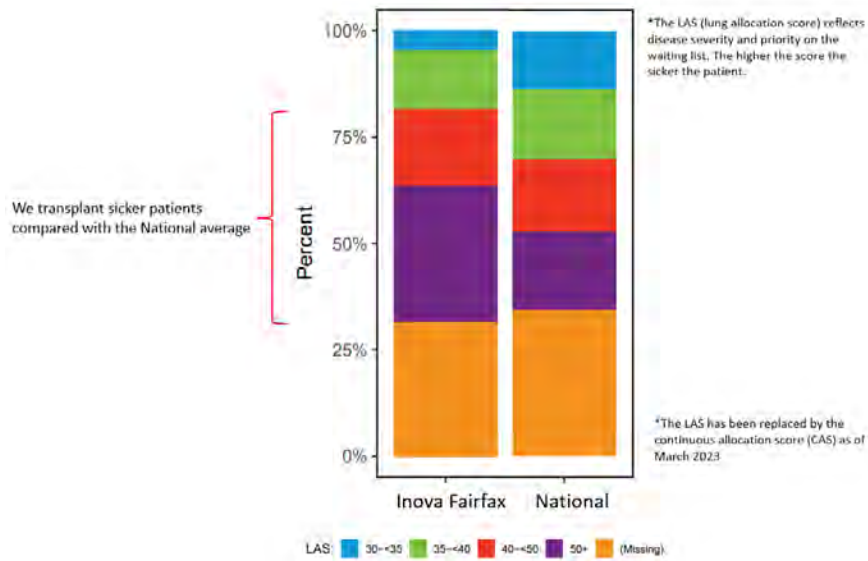


LUNG TRANSPLANT-how we compare to the National Averages-select metrics

Distance traveled to procure lungs



LAS at the time of transplant



Data from UNOS Benchmark report (October 2023)



Pulmonary Hypertension Program Update (by Oksana Shlobin)

The Pulmonary Hypertension (PH) Program at Inova Fairfax Hospital continues to thrive. We currently follow **430 patients with all five WHO groups of PH, which is 16% growth from the previous year**. The multidisciplinary CTEPH program continues to grow with **21 pulmonary thromboendarterectomies to date with 0% mortality**, a median LOS of 7 days and excellent hemodynamic results. We are one of the few programs in the country to offer the alternative option of **balloon pulmonary angioplasty** in patients with distal vascular disease. This procedure is performed by the dynamic duo of Drs. Hong Lim (IR) and Behnam Tehrani (IC) with **over 30 procedures** in 9 patients to date, accompanied with excellent outcomes. We hold monthly regional multi-disciplinary CTEPH and PH meetings to discuss clinical cases and provide literature update. If you are interested in virtual participation (to listen in or present a case) at either meeting, please contact either Oksana.shlobin@inova.org or astrid.munoz@inova.org.

In addition to providing cutting edge clinical care, we remain committed to clinical research and offer patients an opportunity to participate in a variety of clinical trials for various groups of PH, including Group 1 PAH, ILD-PH and HFpEF-PH. An exciting Phase 3 study of inhaled servalutinib, a potential disease modifying tyrosine kinase inhibitor, for Group 1 PAH will be up in running in the new year. If you are interested in referring a patient for a clinical trial consideration, please email Oksana or Vik Khangoora, who just assumed the position of an Associate Director of the Pulmonary Hypertension Program (**congrats Vik!**).

Our team members continue to present at international, national, and regional conferences including ISHLT, ATS, Chest/ACCP, ERS, and contribute to research in the field of PH. We always strive to be active in outreach to increase awareness of this disease and provide education to both the provider and patient community. The 2023 PH Education Day held in November, a PH Awareness month, attracted over 100 participants from the region.



PH Education Day



PH Education Day



PHA O₂ Breath Walk

We welcome your referrals and are dedicated to partner with you in care of this complicated patient population. Please don't hesitate to contact Oksana or Vik at:

Oksana.shlobin@inova.org (571) 314-1645 cell

vikramjit.khangooraa@inova.org (410) 865-9672 cell

Referrals can also be directed to our dedicated intake coordinator **Arti Sharma** via email

phreferrals@inova.org

[phone \(703\) 776-6168](tel:7037766168)

[fax \(703\) 776-3115](tel:7037763115)



Inova Adult Cystic Fibrosis & Bronchiectasis Program – 2023 Update
(by Anju Singhal and Alan Nyquist)

Cystic fibrosis (CF) continues to be one of the most remarkable stories in medicine. Since the approval of the transformative CFTR modulator drug, Trikafta® (Elexacaftor-Tezacaftor-Ivacaftor) in October 2019, life with CF has dramatically improved for nearly 90% of adults with CF. We have seen sustained improvements in lung function, nutritional status, and quality of life. This has resulted in less pulmonary exacerbations, hospitalizations, and lung transplants for CF (only 53 in the US in 2022).

Trikafta continues to be a game changer --- but the CF community is still diligently searching for a transformative therapy for the remaining 10% of people with CF who do not benefit from this therapy based on their gene mutations.

Statistics on our Adult CF Program at Inova:

- We currently care for approximately 179 adults, 85% are enrolled in the CF Foundation Patient Registry
- We have a diverse CF population. See how our patient demographics compare to the national values:

	Inova Values	National Values
Males (%)	54.7	51.7
Females (%)	45.3	48.3
Race – White (%)	84.6	93.1
Race – Black (%)	5.1	4.7
Ethnicity – Hispanic (%)	12	9.6
Genetics – F508del Homozygous (%)	36.8	43.7

- 33 patients (18%) have Advanced Cystic Fibrosis Lung Disease (ACFLD).
- 16 patients (9%) have received a lung transplant.
- 130 patients (73%) represent a more standard CF population.

We have great outcomes due to our growing multidisciplinary team, adherence to guideline-based care, and high use of CFTR modulators with 93.8 % of our eligible patients prescribed Trikafta® compared to the national average of 90.4%. Speaking of our growing team, we have had great additions to our team this year:

- Dr. Ryan Tewell joined as our CF Pharmacist.
- Angeliz Figueroa Cruet joined as our CF pharmacy liaison.
- Cassandra Rush joined our team as a therapist in December 2023.

We practice patient and family centered care that is informed by our CF Patient Family Advisory Board. Our board is a blend of people with CF, caregivers, and Care Team Members who meet monthly to help improve the care experience at Inova. Projects have included: hospital admission “welcome bags” for people with CF and the creation of a successful CF Food Pantry in our clinic space to provide healthy food and grocery store gift cards to those with food insecurity. We also

partner with the Food and Friends program to provide home-delivered medically tailored meals to some of our CF patients.

Why send your CF patients to us for evaluation?

- We can facilitate CF gene sequencing and prescribe CFTR modulators if eligible (including doing the prior authorizations!)
- We have a multi-disciplinary team to provide holistic care and support physical and mental wellbeing.
- Patients can participate in the CFF Patient Registry which drives care and research initiatives on the national level.
- We can connect patients with CF specific resources and programs to enrich their lives.
- We can facilitate clinical trial enrollment and referral for patients who are not modulator candidates.
- We practice CF care guidelines and order/interpret routine testing such as DEXA scans, oral glucose tolerance tests, vitamin testing, and appropriate cancer screening (example, CF patients have a higher risk of colon cancer).

In addition to CF, we care for non-CF bronchiectasis patients and welcome referrals!

Why send your bronchiectasis patients to us for evaluation?

- **We can facilitate sweat testing and CF gene sequencing to evaluate for CF.**
 - **It is never too late to diagnose CF:** We have been seeing an increase of patients diagnosed with CF as an adult. One of our recent patients was 73 years old when her bronchiectasis was finally diagnosed definitively as CF on a sweat test!
 - **CF is not just a disease of Caucasians.** It needs to be considered in people of all races and ethnicities who have unexplained bronchiectasis or other suggestive symptoms. 12% of our patients identify as Hispanic, and we care for many patients with CF from a variety of racial and ethnic backgrounds who benefit from comprehensive CF care.
- We have a multidisciplinary team that provide nutritional, social work, respiratory therapy, nursing, pharmacy, mental health, and infectious disease support.
- We do respiratory cultures and spirometry at every visit.
- Our Respiratory Therapist will do 1 on 1 airway clearance training sessions with patients to find what works best for them.

Epic Chat us at:



IHS Adult Cystic Fibrosis Team

Opt-In

Number of Members: 8

For Appointments email:

CFappointments@inova.org or
bronchiectasisa@inova.org

Phone: 703-776-7876

Fax: 703-776-3515

Or contact us directly:

Anju.singhal@inova.org – Cell phone: (865) 621-5942 – call or text!

Alan.nyquist@inova.org – Cell phone: (518) 339-4043 – call or text!



ILD Program Update 2023 (by Chris King)

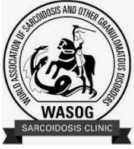
This year was a return to “business as usual” for the interstitial lung disease (ILD) clinic. ILD remains the largest population we care for in the Inova Advanced Lung Disease and Transplant Clinic, with over 1,000 unique ILD patients. We continue to be the only accredited Pulmonary Fibrosis Foundation center in the area and one of only two in the state. We received our ILD re-accreditation in December of this year after a very successful visit by the Pulmonary Fibrosis Foundation. Our combined pulmonary/rheumatology clinic for complex connective-tissue disease associated ILD cases has been quite successful and is now being offered twice a month. We also continue our monthly multi-disciplinary pulmonary pathology meeting, where our pulmonary group, thoracic radiologists, thoracic surgeons, and our pulmonary pathologist review biopsies and discuss challenging cases. This meeting is held via Zoom, so if you have a case you wish to present, please email astrid.munoz@inova.org for an invitation to the meeting.

Our research efforts into ILD continue as well. We continue to be very active in IPF and ILD clinical trials and currently have 3 IPF studies actively recruiting. We are the largest recruiter worldwide into the TETON trial of inhaled Treprostinil for IPF with 25 patients enrolled thus far. (Study of Efficacy and Safety of Inhaled Treprostinil in Subjects with Idiopathic Pulmonary Fibrosis - Full Text View - ClinicalTrials.gov). Our very own Steve Nathan is the chair of the steering committee for this study as well as its “sister” study TETON-PPF which will look to recruit patients with progressive pulmonary fibrosis of other causes.

As always, we appreciate your referrals. If you have patients you wish to refer or a case you wish to discuss, please email **Dr. Christopher King** at Christopher.king@inova.org or call **703-953-7837 (cell)**.

Team Inova at the Pulmonary Fibrosis Walk DC October 2023





Sarcoidosis Update: 2023 (by Shambhu Aryal)

For more than 20 years, pulmonary sarcoidosis has been a vital part of Inova's advanced lung disease services. This year was a landmark year for our sarcoidosis program. We were designated a Center of Excellence by the **World Association of Sarcoidosis and other Granulomatous Disorders (WASOG) in June**. We are now one of **46 such centers in the world, of which 33 are in the United States**. This designation is provided by WASOG to sarcoidosis centers with fully integrated capabilities, proven sustainability over years, leadership, best practices, research, support, and training for sarcoidosis patients and professionals. We also remain in active collaboration with the Foundation for Sarcoidosis Research as we are one of the few founding Foundation for Sarcoidosis Research Global Clinic Alliance members.

Sarcoidosis remains an important contributor to our interstitial disease and pulmonary hypertension programs, as well as an important indication for lung transplantation at our center. Dr. Shambhu Aryal leads the sarcoidosis clinic. Besides pulmonology, our multidisciplinary team includes representation from cardiology, dermatology, neurology, and ophthalmology to ensure comprehensive care to patients with coexisting or isolated non-pulmonary manifestations of sarcoidosis. Dr. Mitchell Psotka, Section Chief of Advanced Heart Failure and Heart Transplantation is the lead cardiologist for the Sarcoid Center and Dr. Rahul Dave is our neurologist. Dr. Abbas Reza Emaminia is the director of Advanced Cardiac Imaging, and Dr. Pooja Singh is the lead rheumatologist. We also had a new cardiologist, Dr. Sumeet Mittar and a new neurologist, Dr. Amy Safadi join our team this year. Our monthly multidisciplinary sarcoid conference (held on the 2nd Friday of every month at 7:30 am) has been going on for three years now with participation from pulmonologists from other medical centers.

We are actively recruiting for the Efzofit study, a global phase 3 trial of Efzofitimod. We also are still recruiting for a multicenter phase 2 trial of namilumab in pulmonary sarcoidosis. Besides the benefit of the clinical trials, our patients with sarcoidosis also get to be assessed for the need for lung and heart-lung transplantation early on due to the availability of lung transplantation services at our program. If you have patients you wish to consider for these trials or for lung transplantation, please contact **Dr. Shambhu Aryal at shambhu.aryal@inova.org or at 703-776-5427**.

Space filler...



It always gives us great pleasure and gratification when we see our post-lung transplant recipients enjoying their lives to the full. (with patient permissions)

Patient Education & Support Groups-2024

Transplant:

We hold a virtual monthly Transplant Education Group to which all our pre-transplant and post-transplant patients are welcome. It is an expectation that our listed patients attend this group as it also functions as an education forum with specific topics and speakers on a monthly basis. The group meets virtually the 1st Tuesday of every month from 1:00-2:00 pm. For more information, please contact Elizabeth Davies at 703-776-8027 or elizabeth.davies2@inova.org.

New this year we also have a Post-Transplant Support Group exclusively for post heart and lung transplant patients. This is a patient focused support group led by the transplant social work team and is designed to provide a place for our patients to talk about their transplant experience. The group meets virtually every other month on the 3rd Thursday from 12-1pm. 2024 Dates: 1/18, 3/21, 5/16, 7/18, 9/19, & 11/21. For more information, please contact Dianne Duke at 703-776-5776 or dianne.duke@inova.org.

Pulmonary Fibrosis/Interstitial Lung Disease:

The Pulmonary Fibrosis Support Group of Greater Washington DC is a virtual monthly support group intended for patients, families, and caregivers of those diagnosed with pulmonary fibrosis or interstitial Lung Disease. Group format includes educational presentations with a specific topic each month. The virtual group meets the 4th Tuesday of every month (except December) from 1:00-2:00 pm.

Coffee Among Friends is a virtual, patient run support group sponsored by the Pulmonary Fibrosis Foundation. This support group was developed to join patients, families, and caregivers together who are being affected by pulmonary fibrosis. Through the sharing of experiences, group members are able to provide encouragement, sharing of resources and support. The group meets the 2nd Monday of each month from 11:00-12:00 pm.

For more information, please contact Dianne Duke at 703-776-5776 or dianne.duke@inova.org.

Sarcoidosis:

In partnership with the Foundation for Sarcoid Research (FSR) we have a peer lead monthly support group for our patients living with Sarcoidosis. The FSR Sarcoidosis Community Group of Fairfax at Inova meets virtually on the 3rd Thursday of every month from 1-2pm. For more information, please contact Elizabeth Davies at 703-776-8027 or elizabeth.davies2@inova.org.

Pulmonary Hypertension:

Our PH Support Group is patient run and intended for all patients with any form of pulmonary hypertension. For more information, please contact our nurse, Patricia Jackson, at 703-776-5601 or patricia.jackson@inova.org

KUDO CORNER

Below are some excerpts from patient comments during the course of 2023. Obviously, we are only going to include the positive ones 😊, but overwhelmingly the comments we received during the year were positive.

General patient comments for 2023 clinic visits:

- "Providers listened to my concerns, were respectful, and gave me lots of information and treatment options that were very helpful, It was very refreshing and refreshing to hear their thoughts and recommendations."
- "A well balanced, dedicated team who not only seemed very concerned for me but also one another."
- "Everything seems to move in an efficient way at Inova"
- "All of the staff throughout the Hospital was exceptional. Some were on their way home, but stopped to ask if we needed direction or support. We have never experienced just true care from the entire Hospital as we did today. Truly will recommend Inova to everyone. Everyone was so patient and attentive to all the patients everywhere."
- "Everyone took the time to explain everything to us. We finally believe we are at the right place to help get us answers. We cannot say thank you enough."
- "I have been to 5 star medical facilities in 6 different countries, and none come close to INOVA."
- "When I leave my appointment I feel excellent about my office experience. Everyone that I interact with is kind and caring."
- "Just GRAND"
- "I have never had a bad experience at INOVA with my medical care and SINCERELY appreciate each of my care givers and their support staff."
- "The INOVA Lung Center is a first class operation."
- "The pre-transplant team is phenomenal-everyone is so nice and informative every time. It really relieves a lot of anxiety knowing they are there for anything I need."

INOVA ADVANCED LUNG DISEASE & TRANSPLANT RESEARCH-2023 UPDATE

The backbone of our research are our 3 research nurses, 5 clinical research coordinators, a research assistant and a regulatory specialist under the leadership of our research director, Edwinia Battle. Our site participates in numerous clinical trials for a variety of lung diseases including interstitial lung disease and IPF, sarcoidosis, lung transplantation, pulmonary hypertension, chronic obstructive pulmonary disease including A1AT deficiency/COPD-PH, CF, and non-CF bronchiectasis.

We have the following clinical drug trials currently **enrolling**, **coming soon(ish)**

- **Idiopathic Pulmonary Fibrosis:** Studies now taking patients with FVCs as low as 45%. All our IPF studies allow patients to enter on standard of care antifibrotic therapy.
 - Teton- A Randomized, Double-blind, Placebo-controlled, Phase 3 Study of the Efficacy and Safety of Inhaled Treprostinil in Subjects with Idiopathic Pulmonary Fibrosis
 - Novartis platform study of multiple drug candidates.
 - Tvardi phase 2 study of TTI-101. 12 week study
- **Interstitial Lung Disease:**
 - FIBRONEER-PPF: for patients with progressive pulmonary fibrosis (PPF) (Boehringer-Ingelheim)
 - Phinder Study- screening study for pulmonary hypertension complicating ILD.
 - Inhaled Pirfenidone PPF (Avalyn Pharma). Projected start Q1 2024
- **Sarcoidosis:**
 - RESOLVE study: Kinevant study of Namilumab (anti-GM-CSF monoclonal Ab)
 - aTyr study of ATYR1923 (extracellular immunomodulator)
- **Pulmonary Arterial Hypertension:**
 - TORREY study of inhaled Seralutinib for PAH. Up and running Q1 2024. Gossamer Bio
- **Multidrug-resistant Mycobacterium Abscesses Complex Infection:**
 - Bacteriophage- Individual Consent for Voluntary Participation in Compassionate Use of Bacteriophage Therapy for Treatment of Multidrug-resistant Mycobacterium Abscesses Complex Infection
- **Non-Tuberculous Mycobacteria:**
 - Clofazimine Multiple Patient Program

Please see our website for additional information on our research studies:

<https://www.inova.org/our-services/inova-lung-services/research>

For all inquiries please email: lungresearch@inova.org or email one of our docs

Inova Lung Transplant and Advanced Lung Disease Team Members (December 2023)



Top Row: Sholet Hampton (CF Nurse Coordinator); Merte Lemma (Research Project Manager); Paige M. Thibodeaux, (Research Coordinator); Taruni Maganti (Research Coordinator); Adam Cochrane (Transplant Pharmacist); Doron Adu-Gyamfi (Research coordinator); Ruth Brower (NIH Coordinator); Jared Wilkinson (ALD and Transplant Fellow); Sarah Scott (Senior Manager); Vik Khangoora, MD (Associate Director of the Pulmonary Hypertension program); Osman Malik, MD; Megan Harvey (Pre-transplant coordinator); Dianne Duke (Social Worker); Becky Packer (Transplant Coordinator); Tina Jackson (PH coordinator); Susan Mam (Transplant Coordinator); Shannon Spada (Transplant Nutrition Educator); Morgan Wahl (Inpatient Nurse Coordinator); Anastasia Maczko (Transplant Nutrition Educator); Julie Torres (ALD coordinator); and Jeannine Schulte (Transplant Coordinator).

Second row: Olivia Kaplan (Research Regulatory); Jocelyn Melendez (Practice Manager); Priscilla Dauphin, RN (Research Coordinator); Liz Portugal- Paredes (PAA); Thao-chi Vo (Research Coordinator); Colleen Mann (Research Coordinator); Edwinia Battle, RN (Research Director); Jessica Chun (Post-transplant NP); Astrid "Julieth" Munoz (Sr. Program Manager); Janiece Lacy (LNP); Anju Singhal, MD (Transplant Pulmonologist, Medical Director CF program); Adriana Kochi (Quality Manager); Dana Prasanna (Transplant Quality Coordinator); Ellen "Lennie" Chaisson (Transplant Quality Coordinator); Johanna Coughlin (PH Nurse Coordinator); Patricia Jackson (PH Nurse Coordinator); Elizabeth Davies (Social Work Manager); and Ana Perez Reyes (Transplant Coordinator).

Front Row: Rachel Guinther, RN (Research Coordinator); A. Whitney Brown, MD; (Transplant Pulmonologist); Yaa Serwaah (Inpatient Transplant NP); Lauren Marinak, (Inpatient Transplant NP); Steven Nathan, MD (Medical Director, ALD and Lung Transplant Programs); Shambhu Aryal, MD (Medical Director, Lung Transplant Program and Sarcoidosis Program); Alan Nyquist, MD (Associate Medical Director CF program, Transplant Pulmonologist); Oksana Shlobin MD (Medical Director PH Program, Director of Outreach and Education); Debbie Campbell (Sr. Director Thoracic Programs); Meg Fregoso (Post-transplant NP); and photobomber 😊

Missing in action:

Administration: Lenora Hall, NP (Clinical Manager); Deanna Ridgeway (Financial Manager); Research: Megan Harbor (Research Coordinator); Docs: Chris King, MD (Medical Director ALD & Transplant Critical Care, Director ILD program, Director CVICU); Dan Tang, MD (Surgical Director); Dr. Kate Klein, MD (Transplant Surgeon); Chris Thomas, MD (Transplant Pulmonologist); Ancillary Support: Carlos Coronel (Sr. Admin Coordinator); Arti Sharma (Referral Coordinator); Janah Bernabe (Referral Coordinator); Stephanie Vargas (Referral Coordinator); Rosa Uribe (Financial Coordinator); Lori Hill (Financial Coordinator); Carmen Reyes; (Financial Coordinator); Coordinators: Michelle Kopp (Inpatient PA).

Providers:



Left to right: Yaa Serwaah, Vik Khangoora, Alan Nyquist, Lauren Marinak, Anju Singhal, Whitney Brown, Oksana Shlobin, Steve Nathan, Shambhu Aryal, Jared Wilkinson

Nurse Coordinators:



Back row: Tina Jackson, Julie Torres, Patricia Jackson, Morgan Wahl, Becky Packer, Megan Harvey, Susan Mam, Sholet Hampton
Front row: Johanna Coughlin, Ana Perez Reyes, Jeannine Schulte, Janiece Lacy

Research Coordinators:



Back row: Merte Lemme, Colleen Mann, Priscilla Dauphin, Olivia Kaplan, Thao-chi Vo, Doron Adu-Gyamfi
Front Row: Edwinia Battle, Paige Thibodeaux, Rachel Guinther, Taruni Maganti

Academic Accomplishments 2023 (Inova authors bolded)

ORIGINAL RESEARCH MANUSCRIPTS:

PUBLISHED

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2. Abhimanyu Chandel, **Christopher S. King**, Rose Ignacio, **Oksana A. Shlobin**, **Vikramjit Khangoora**, **Shambhu Aryal**, **Alan Nyquist**, **Anju Singhal**, Kevin R. Flaherty, **Steven D. Nathan**. External Validation and longitudinal application of the DO-GAP index to individualize survival prediction in IPF patients. *ERJ Open Res* 2023; 9: 00124-2023 [DOI: 10.1183/23120541.00124-2023].
3. Jürgen Behr, **Steven D. Nathan**, Ulrich Costabel, Carlo Albera, Wim A. Wuyts, Marilyn K. Glassberg, Harold Haller Jr, Giuseppe Alvaro, Frank Gilberg, Katerina Samara, Lisa Lancaster. Efficacy and safety of pirfenidone in patients with advanced versus non-advanced idiopathic pulmonary fibrosis – post-hoc analysis of six clinical studies. *Adv Ther.* 2023 Sep;40(9):3937-3955. doi: 10.1007/s12325-023-02565-3. Epub 2023 Jun 30. PMID: 37391667
4. Aaron Waxman, Ricardo Restrepo-Jaramillo, Thenappan Thenappan, Peter Engel, Abubakr Bajwa, Ashwin Ravichandran, Jeremy Feldman, Amy Hajari Case, Victor Tapson, Peter Smith, Chunqin Deng, Eric Shen, **Steven D. Nathan**. Long-term Inhaled Treprostinil for Pulmonary Hypertension Due to Interstitial Lung Disease. *Eur Respir J.* 2023 Apr 20:2202414. doi: 10.1183/13993003.02414-2022. Online ahead of print. PMID: 37080567
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7. Daniel A. Culver, **Shambhu Aryal**, Joseph Barney, Connie C.W. Hsia, W. Ennis James, Lisa A. Maier, Lucian T. Marts, Ogugua Ndili Obi, Peter H.S. Sporn, Nadera J. Sweiss, Sanjay Shukla, Nelson Kinnersley, Gennynne Walker, Robert Baughman. Etezofitimid for the treatment of pulmonary sarcoidosis *CHEST* 2023; 163(4):881-890
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ACCEPTED or EPUB

1. Paul Ford, Michael Kreuter, Kevin K. Brown, Wim A. Wuyts, Marlies Wijsenbeek, Dominique Israël-Biet, Richard Hubbard, **Steven D. Nathan**, Hilario Nunes, Bjorn Penninckx, Niyati Prasad, Ineke Seghers, Paolo Spagnolo, Nadia Verbruggen, Nik Hirani, Juergen Behr, Robert J. Kaner, Toby M. Maher. An adjudication algorithm for respiratory-related hospitalization in idiopathic pulmonary fibrosis. Accepted ERJ Open Research 11/08/2023
2. **Steven D. Nathan**, Benham Tehrani, Qiong Zhao, Rafael Arias, Dennis Kim, **Antonia Pellegrini**, **A. Claire Collins**, **Jack Diviney**, Shourjo Chakravorty, **Vikramjit Khangoora**, **Oksana A. Shlobin**, **Christopher Thomas**, Ben R. Lavon, **Christopher S. King**, Abhimanyu Chandel. Pulmonary Vascular Dysfunction without Pulmonary Hypertension: A Distinct Phenotype in Idiopathic Pulmonary Fibrosis. Accepted to Pulm Circ 11/05/2023.
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1. Abhimanyu Chandel, Sachin Gupta, Joshua Galanter, Yiling Chen, **Steven D Nathan.** External Validation and Longitudinal Application of a Multidimensional Index to Individualize Survival Prediction in Idiopathic Pulmonary Fibrosis. Submitted to ATS 2023
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3. **Christopher Thomas, Katherine Klein, Jamie L. W. Kennedy, Mitchell Psocka, Iyad Isseh, Daniel Tang, Shambhu Aryal, Vikramjit Khangoora, Alan Nyquist, Anju Singhal, Onix Cantres Fonseca, Oksana Shlobin, Steven D. Nathan, Christopher S. King**. Heart-Lung Transplantation for Restrictive Cardiomyopathy and Pulmonary Hypertension due to Emery-Dreifuss Muscular Dystrophy. ISHLT 2023
4. **Lauren Marinak, Medha Mani, Shambhu Aryal**. Phlegmasia Cerulea Dolens in a Post Lung Transplant Recipient: A Case Report
5. **Morgan Wahl, Adam Cochrane, Margaret Fregoso**, Jamie L.W. Kennedy, **Shambhu Aryal**. Use of donor-derived cell free DNA in heart/lung transplant recipients

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Sean Agbor-Enoh, Michael Keller, **Steven D. Nathan**, Joby Matthew, Hyesik Kong, Moon Jang, Pali Shah, Palak Shah, Maria E. Rodrigo, Keyur Shah, Matt Kelly, **Merte WoldeHanna**, Elizabeth Semarge, Joyce Johnson, Leila Sounna, Ruth Brower. Genomic Research for Transplantation (GRAFT): a model to access patients and promote NHLBI DIR research

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1. **Nathan SD**; Tapson VF; Levine D; Rischard F; Cassady S; DuBrock HM; El-Kersh K; Tarver J III; Smith P; Deng CQ; Shen E; Waxman AB The Importance of Early Treatment with Inhaled Treprostinil in Patients with Pulmonary Hypertension Associated with Interstitial Lung Disease: A Post-hoc Analysis of the INCREASE Open-label Extension
2. El-Kersh K, Bag R, Bhatt N, **King C**, Waxman A, Kim H, Cella D, Shen E, **Nathan SD**. Derivation of a simple risk calculator for predicting clinical worsening in patients with pulmonary hypertension due to interstitial lung disease.

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