

## **OPTN Lung Transplantation Committee**

### **Meeting Summary**

**May 13, 2022**

**Chicago, Illinois/Conference Call**

**Erika Lease, MD, Chair**

**Marie Budev, DO, Vice Chair**

### **Introduction**

The Lung Transplantation Committee (the Committee) met via Citrix GoTo teleconference on 5/13/2022 to discuss the following agenda items:

1. OPTN Donation after Circulatory Death (DCD) Lung Transplant Collaborative
2. OPTN Policy Oversight Committee (POC) Update
3. Lung Allocation Score (LAS) Refit
4. Lung Review Boards
5. Heart ABO Blood Type Incompatible Project
6. Updating Mortality Models
7. Brainstorm and Open Forum
8. Next Steps and Closing Comments

The following is a summary of the Committee's discussions.

#### **1. OPTN Donation after Circulatory Death (DCD) Lung Transplant Collaborative**

The Committee received an overview of the project and programs that are involved in the collaborative project.

The aim of the collaborative is the following:

- Develop an Improvement Guide with effective practices and resources gathered from practice model organizations.
- Provide focused time, space, and support for programs to collaborate with peers while working simultaneously on improvement projects.

#### Summary of discussion:

A member inquired about contact information to get involved in the project. A member stated that they would share the contact information by email with the Committee.

#### **2. OPTN Policy Oversight Committee (POC) Update**

The Committee Vice Chair provided an update on the work of the OPTN Policy Oversight Committee (POC). This included the following topics:

- POC membership
- Role in policy development
- Project approval process
- Project prioritization
- Portfolio management – project benefit

- Project capacity
- Impact on committee projects

Summary of discussion:

Staff added that the Committee is seeing the shift already in seeing the details of a project earlier in development. A member asked if there would be an overall budget increase for the OPTN work or if there will be more mindful allocation of the already available resources. Staff added that an overall budget increase is being looked at and the Vice Chair mentioned that the POC will be looking more at projects and how they meet specific strategic goals.

**3. Lung Allocation Score (LAS) Refit**

Scientific Registry of Transplant Recipients (SRTR) presented the lung allocation score (LAS) refit – oxygen (O<sub>2</sub>) by ventilation interaction. The LAS was recently refit using an updated cohort of candidates and, in the implementation phase, it was noted that United Network for Organ Sharing (UNOS) and SRTR were deriving different LAS values for ventilated candidates.

Summary of discussion:

A member asked how time of intubation is reflected and SRTR added that a candidate's status can change over time, but this looks at you're the candidate's predicted survival given the current circumstances on a specific day.

An attendee added that the interaction model makes sense to them because if you have a patient that requires more oxygen regardless of ventilation status, you need to consider the interaction and include it. SRTR mentioned that they are currently not including this interaction, so the question becomes if it should be kept the way it is currently or does the Committee want to include the interaction. The SRTR representative also noted that 10 percent of the population has an LAS of 53 or higher, but it is the sickest 10 percent. A member mentioned, from a surgical perspective, that they need to have the highest LAS within a 250 nm radius in order to get those offers, so having a high score is beneficial so the change to the interaction model may be a different question.

SRTR stated that the middle cohort, who has a huge risk of mortality, may be underserved because the model overcompensates for those high LAS candidates. Those middle LAS scores still have a higher mortality and the goal should be to get those candidates transplanted before they are sicker. The SRTR representative also noted that this group has worse outcomes as well.

A member stated that this should be accounted for in continuous distribution since the score is moving to a 1:1 ratio and SRTR clarified that the waitlist mortality models are stronger than the post-transplant survival models. A member mentioned that there obviously is an interaction, since the amount of fraction of inspired oxygen (FiO<sub>2</sub>) is going to be different if a candidate is on a ventilator and the candidate's score should account for that. The important part is that the person on high flow and the person on the ventilator are not very different and the models are underestimating how sick that group on high flow is. By inflating the scores at the high end, the high flow group is being disadvantaged in a way because they won't get the offers, then within 3 months they're on the ventilator. A member mentioned that the mortality and survival for that middle cohort may be similar to those high LAS candidates who are on a ventilator but may be disadvantaged by the overcompensated score.

A member stated that the numbers showing the interaction make a lot of sense, but asked if there are candidates with 80-90 LAS in the interaction model and how candidates would get there with the proposed changes. SRTR said the 95<sup>th</sup> percentile is 76 and 99<sup>th</sup> percentile is 94.1. The member asked how a candidate gets to those high LAS scores and it was stated that when a patient is on a ventilator, that is

accounted for, and their six minute walk (6MW) goes to zero, etc. The SRTR representative stated that they chose median variables to do the calculations, but there is a cohort of patients on ventilators for whom other parameters may be worse than the median.

A member asked if SRTR thought about incorporating oxygen as a nonlinear variable since oxygen is not a linear predictor of survival. SRTR said that was not considered for this model. A member said that the only way candidates get transplanted in their region is with very high score and did not see how a candidate with a median LAS can compete with higher LAS candidates. The member hoped that the move to continuous distribution would help.

SRTR clarified that minimizing the difference in points between the candidates may help address that issue by having a delta of 20 points between the median and high score candidates versus 40 points. SRTR asked if the practice is to push candidates into higher LAS and if that should be considered. A member mentioned with current use of one year survival, LAS does play a role. Given an option, they would suspect the ventilator patient to have a poorer survival so not including the interaction captures that point. SRTR mentioned that there is such little variation in post-transplant survival in LAS, so LAS is much more reflective of waitlist mortality.

A member stated that centers could be reluctant to transplant those with better expected survival if they're going to be dinged for doing so. SRTR stated that no one should be dinged if the whole country moves to the same model, and that it is hard to predict survival. A member stated that the Committee is trying to decide what modeling is fair and felt that if the person a day from being ventilated is just as sick as the person ventilated, then this change to the mortality models should be put out for public comment and considered. An attendee added that if an idiopathic pulmonary fibrosis (IPF) patient comes in and is instantly ventilated, that is a super sick, urgent candidate. SRTR stated that these numbers are just for the Committee to think about the interaction between O2 and ventilation and they are reflective of the average candidate. SRTR emphasized that the actual number of days is not as important as the relationship between the number of days. SRTR said the urgency of that kind of candidate would be reflected in their changed values.

A member stated that they struggle with this clinically and inquired if SRTR thinks that the use of extracorporeal membrane oxygenation (ECMO) or something else is messing with the ventilation expected wait list survival in some fashion. SRTR stated that when a candidate is at an extreme end of a spectrum then ventilation probably makes no difference because other factors indicate the degree of the candidate's illness. The Chair added that since the modeling informs the Committee's decisions, it is important to make sure that things are consistent.

A member asked if there is any way to change the shape of the weighted variables to reflect that the candidates who are on the same amount of oxygen as a candidate who is ventilated and SRTR asked if members are seeing that clinically and members agreed they do. A member stated that there are definitely times when a candidate is on high flow/high liters, and they just stop walking. A member stated that once you're dealing with 99<sup>th</sup> percentile, the numbers get smaller and smaller and inquired if, clinically, the evaluation of this interaction is off.

A member stated that what's not captured here is that once candidates are on the ventilator, there are all the possible complications from being on the ventilator. A member stated it may feel like the ventilator patient is sicker because of the resource utilization; however, there will be resource utilization on the back end if there is competition for patients to get sicker and sicker. A member stated they hoped that this does not encompass candidates who are on ECMO since ECMO has even more increased risk. SRTR explained that this is not a risk prediction model; it's just looking at the relationship between ventilator and oxygen, so the question is, when someone is on a ventilator should we think about

oxygen differently? A member said that they highly doubt a program would go through the evaluation of a diagnosis group D candidate if meeting them on a ventilator and members stated that large programs sometimes do meet a patient on the ventilator.

#### Next Steps:

The Committee agreed to discuss this further as a possible future project and consider how to address any concerns.

#### **4. Lung Review Boards**

The Committee reviewed the policy, guidance, and operational guideline changes to lung review boards and voted on those changes to go out in a proposal during the Summer 2022 Public Comment cycle.

#### Summary of discussion:

A member asked if freestanding children's hospitals are included and staff clarified they would be. The Vice Chair asked if this would be the standard for all organs moving forward and staff clarified that lung would likely be different since the transplant volumes for lung are lower than other organs.

A member asked for clarification on the rotation and staff clarified that programs would be on for two years then off for three years. The Vice Chair asked if there should be discussion on the experience of the people appointed to review cases and it was clarified that the current version does not include expectations or guidelines for experience. A member asked if there was a number of years in practice that may be appropriate, or if there would be a minimum number of years of experience for primaries and alternates. The Vice Chair also noted that this will be a new process and system with continuous distribution that will have to be learned by members. A member noted that sometimes the democratic nature of the review is problematic and members felt that the reviewer responses should be blinded because they can heavily influence the votes of other reviewers. Members felt that five years of experience for the primary and three years for the alternate was reasonable.

A member asked if the appeal defaults to the same nine people that initially reviewed and staff clarified that it would unless one of the initial reviewers is out of office. A member asked if pediatric exceptions would be reviewed by adult clinicians and staff clarified that there would be an attempt to get pediatric reviewers, but it may not always be possible. The member added that this would be complicated for adult reviewers.

The Vice Chair brought up the instances where a patient is dual-listed and has an exception at the first program but it does not automatically follow the patient to the second program, which disadvantages the patient. Staff clarified that something formal can be added to the guidance or something could be added in education. The Chair mentioned that it may be best included in education since circumstances around the exception may change and a member agreed.

A member asked how the second center even knows that there was an exception and the Vice Chair shared that in their example the first program shared with the second program that the exception was in place. A member asked if there should be something more formal in policy where the score follows the patient, and the Chair said there are circumstances where the patient's status changes and the exception needs to be re-evaluated so should not automatically be given. The Vice Chair noted that it is not uncommon for scores to be different at the dual-listing programs and the Chair said it is the responsibility of the listing program to determine if an exception is needed.

A SRTR representative stated that an exception score implies that the allocation system doesn't serve that patient well, so it is a concern if the same patient has different scores at different transplant centers. For example, if a program has a combined pulmonary fibrosis and emphysema (CPFE) patient

and asks for an exception, but then the patient goes to a different center and the second center doesn't know that they need to apply for an exception, then that patient is underserved. A member inquired how the center could be held accountable for that because it gets into center practice variability. The SRTR representative stated that the center can be held responsible, but the point is that the exception is different than just a difference in LAS scores.

A member stated that a patient shouldn't have two different exception scores. If two centers have been granted an exception for the same patient and one is higher than the other then that's not right for the patient.

A member inquired if there is any guidance on what exception scores centers should be requesting. A member stated that it would depend on who is on the review board but the guidance would really help.

A member suggested that there should be a group of Committee members who will be rolling off the Committee soon but are very familiar with continuous distribution and will be available to assist with review board exceptions and members agreed.

The Vice Chair asked if there is a composition requirement of surgeons and physicians and staff clarified that the requirement is that a reviewer must be either a surgeon or physician.

#### Vote:

Does the Committee approve the review board policy, guidelines, and guidance language as presented?

- Yes – 16 votes
- No – 0 votes
- Abstain – 0 votes

#### Next Steps:

The Committee and staff will look into transparency around exceptions for dual-listed candidates and options for educational offerings.

### **5. Heart ABO Blood Type Incompatible Project**

The Committee reviewed the OPTN Heart Transplantation Committee's *Modify Heart Policy for Pediatric Candidates and Intended Blood Group Incompatible (ABOi) Offers* proposal.

The purpose of this project was to safely expand access to donor hearts for pediatric candidates and reduce volume of discarded donor hearts.

The proposal aims to do the following:

- Modify eligibility criteria for ABOi offers by changing acceptable isohemagglutinin titer eligibility criterion in keeping with current clinical practice and research
- Maintain equitable prioritization of ABOi candidates by creating new 'tertiary' blood type match classification
- Expand eligibility to all pediatric candidates registered on the waiting list before turning 18 years old

Current Heart and Lung Policy: ABOi

- Age less than one
  - Heart = Status 1A or 1B
  - Lung = Priority 1
  - Reported titer within past 30 days

- Age at least one
  - Registered before age two
  - Heart = Status 1A or 1B
  - Lung = Priority 1
  - Titers less than or equal to 1:16 within past 30 days

Lung Policy when Continuous Distribution went into effect: ABOi

- Replaces Priority 1 in current policy with a wait list survival score of at least 1.9073 and everything else remains the same

The Committee was posed the following questions:

- For pediatric candidates who need both a heart and lung:
  - Would it be acceptable/appropriate to consider a candidate eligible for lung with heart as long as they met the heart ABOi criteria?
    - Might have been registered after 2 years old or have titers over 1:16
  - Alternatively, would heart-lung candidates need to meet both heart criteria and lung criteria?
- Does the OPTN Heart Committee need to consider permitting broader access to ABOi lung transplant as a future project?

Summary of discussion:

A member felt that broadening the criteria makes sense, but added that this is a very small population in the lung community. The member noted that discussion to expand the age cut off may be needed since it makes sense to allow for older candidates. The member felt following the heart criteria made sense, but may need to allow for older lung candidates. The presenter discussed the very small number of pediatric heart-lung recipients and also the number of candidates currently on the waitlist and the number of removals due to death. Staff clarified that ABOi is allowed for candidates 0-11 years old and wanted to know if the Committee would support limiting the age of the candidates to align with the proposed heart policy. Members discussed that the lung match would stay the same, but only the heart-lung candidates would follow the proposed heart criteria.

There was no further discussion.

**6. Updating Mortality Models**

The Committee reviewed the Updating Mortality Models project which is slated for Summer 2022 Public Comment.

The following are the proposed changes:

*Add to Waitlist (for pulmonary hypertension patients only)*

- New York Heart Association (NYHA) Functional Classification
- B-type natriuretic peptide (BNP) or N-terminal pro B-type natriuretic peptide (NT-proBNP)
- Pericardial Effusion

*Add to Waitlist (for all patients)*

- Recurrent Pneumothoraces
- Bronchopleural fistula (BPF)
- Massive Hemoptysis, number of times in the last year
- Exacerbations, number of times in the last year

- Prior Lung Surgery
- Pleurodesis
- Prior Cardiac Surgery
- Microbiology
- Diffusing Capacity of the Lungs for Carbon Monoxide (DLCO)
- Mean Right Atrial Pressure (mRAP)
- Pulmonary Vascular Resistance (PVR)

#### *Changes to Waitlist*

- Add 'Combined Pulmonary Fibrosis and Emphysema (CPFE)' diagnosis code to Lung Diagnosis Codes
- Revise Diabetes selection options to:
  - Treated with insulin
  - Not treated with insulin
  - Not diabetic
- Revise Assisted Ventilation selection options to:
  - Bilevel positive airway pressure (BiPAP)
  - Continuous positive airway pressure (CPAP)
  - Continuous mechanical – hospitalized
  - Continuous mechanical – not hospitalized
  - Extracorporeal membrane oxygenation (ECMO)
  - Intermittent mechanical – hospitalized
  - Intermittent mechanical – not hospitalized
  - No assisted ventilation needed
- Requires Supplemental Oxygen (O2)
  - Revise selection options to allow for multiple entries and add evaluation date for all three:
    - None
    - At rest
    - With exercise
    - At sleep
  - Proposed units:
    - Max of 100 L/min
  - Add device selection options:
    - Face mask
    - High flow nasal cannula
    - Nasal cannula
    - Reservoir cannula
- Move Six Minute Walk (6MW) Distance field to below Requires Supplemental O2 for better flow of data entry

#### *Remove from Waitlist*

- Percent Predicted Forced Vital Capacity (FVC)
- Post-Bronchodilator Forced Expiratory Volume (FEV)<sub>1</sub>
- Post-Bronchodilator Percent Predicted FEV<sub>1</sub>

#### *Add to Transplant Candidate Registration (TCR) Form*

- Collect data from within the 6 months prior to listing
- Requires Supplemental O2
  - When, how much, delivery
- 6MW Distance
- Massive Hemoptysis (number of times in the last year)
- Actual FVC
- Pre-Bronchodilator Actual FEV<sub>1</sub>
- DLCO

Summary of discussion:

*Massive Hemoptysis, Number of Times in the Last Year*

The Committee was asked if there was a recommended definition for recurrent massive hemoptysis for pediatric candidates or if it would be best practice to leave it to the program's discretion since this is such a small number of the candidate population. A member suggested 3mL over several days which would be applying the same rationale for adults to pediatric candidates and members felt that may be appropriate. Members were in favor of leaving it to the member's discretion regarding what would be considered massive hemoptysis over several days for pediatric candidates and following the 8mL/kg standardized definition for a 24 hour period.

A member asked if a patient having an embolization would add to the risk and if it would be beneficial to ask for that information as well. The Chair noted that their program limits the use of embolization unless completely necessary because of the associated risks and worried that having it defined for data collection in lieu of hemoptysis would be narrowing it down to a very small number of candidates. The member clarified that they would be supportive of not having a volume requirement that needs to be met for massive hemoptysis if an embolization was required. Members were supportive of leaving out the volume requirement in the definition if an embolization was performed.

The Committee also felt that the definition for recurrent bleeding in adults should be very clear in that it should be 100mL each day for more than two days, not 100mL spread over an undefined number of days. A member asked if each day of recurrent count as one occurrence, or is it one recurrent episode counts as one and the Chair felt one episode over several days should be entered as one and the definition should be clear on that.

*Exacerbations*

A member suggested having distinct definitions based on diagnosis, more specifically cystic fibrosis (CF) and chronic obstructive pulmonary disease (COPD). A member suggested looking at the definitions from American Thoracic Society (ATS).<sup>1</sup>

An attendee asked how continuous antibiotics would be handled and the Chair stated that currently this is something where programs ask for exceptions for their candidates. The Chair continued to explain that the hope with this field is to be able to incorporate it appropriately into a candidate's score so they are placed higher than a candidate who is not having exacerbations and then they would be able to be transplanted before the need of continuous antibiotics.

A member noted that steroids should also be included in the proposed definitions and was interested to know if the ATS definitions included that. The Vice Chair agreed that steroid treatment would be good to know and asked about splitting out whether or not the patient is being treated chronically or if it should

---

<sup>1</sup> <https://www.thoracic.org/statements/guideline-implementation-tools/copd-exacerbations.php>



be a certain dosage. Members felt that a dosage above 40 would be appropriate, but could verify that with current clinical practice.

A member noted that the Committee has to be careful when thinking of analyzing this data, since some of this information is very diagnosis specific. The member added that if these data are used in the score in the future, it will have to be diagnosis dependent and members agreed.

Staff asked if it would be easy to associate some of these data with appropriate diagnoses. SRTR added that there is burden for programs to enter information, but there is literature to support that some of these affect mortality, and the Committee should limit new data to what is empirically supported already. They continued to note that the existing fields do not do a good job of capturing the deterioration of COPD patients on the list, so adding steroid treatment may be appropriate.

The SRTR representative also mentioned that for treatment with intravenous (IV) antibiotics, there is an existing data element on the CF registry that is the number of days spent on IV antibiotics during a certain duration which may be appropriate here. The Chair added that the Subcommittee discussed that and ultimately felt that since the CF center is not always at the same place as the transplant program it may be too much of a burden for the transplant program to collect that information.

A member added that we know that patients experiencing exacerbations are very sick, but that they should be connected to diagnosis. The Committee supported including definitions unique to idiopathic pulmonary fibrosis (IPF), CF, and COPD in the proposed language in order to capture diagnosis. Research staff commented that they could look at the interactions of exacerbations for specific diagnoses. The Vice Chair suggested that a percent increase in steroids may be more helpful in identifying exacerbations rather than milligram dosing. A member stated that they have data to share and agreed that information should be collected regarding what listing and referral criteria is being based on. A member asked how can exacerbations between diagnoses be compared, and an SRTR representative noted that it is complicated, but it can be done with adequate sample size.

A member advocated for capturing the number of days of continuous antibiotics and the Chair asked how that information would be captured continuously. The Vice Chair asked if it would be appropriate to have buckets of numbers/ranges. The Chair said the CF Registry captures the number of days in the last year. Members discussed proposing timeframe ranges that are appropriate (i.e greater than 90 days, etc.). A member inquired if a check box would be sufficient to indicate continuous IV antibiotics. A member stated that a total number of days is better. Another member suggested a cutoff such as more than 60 continuous days in the last year. Members felt a more than 60 day cutoff would make sense.

A member asked how successfully the OPTN is gathering data for the non-required fields currently and if the addition of the new fields is going to be successful in capturing this data. A SRTR representative said there are data elements that are problematic that are really important (O2, 6MW) for candidates, but overall the data entry is good. A member stated that these changes may take effort by the programs, but they are necessary.

### *Prior Lung Surgery*

Programs should be able to check multiple surgeries; add the word “open” to the wedge resection value; and add an additional option for video-assisted thoracoscopic surgery (VATS). A member asked if it makes a difference from the surgeons’ perspective if a procedure was done open versus VATS and a member stated that open adds a challenge to transplant while VATS does not change the approach at all.

### *Pleurodesis*

A member inquired if there is any benefit to distinguishing between bilateral and unilateral or if the candidate had multiple pleurodeses. A member stated that understanding the laterality would be nice. A member stated that programs should have the opportunity to check more than one.

Members agreed to add left, right, bilateral and the ability to check more than one.

### *Prior Cardiac Surgery*

Members were supportive, but suggested that it should be an option to select multiple surgeries.

### *Microbiology*

Members suggested putting the strain genomovar III next to *Mycobacterium abscessus* in parentheses and adding *Burkholderia gladioli*. A member suggested adding fungal infections and members added that it would be a very small population. The Chair asked if there is data that state fungal infections result in worse outcomes and the Vice Chair noted there are few instances and suggested waiting on collecting that information until there is something definitive.

### *Diffusing Capacity of the Lungs for Carbon Monoxide (DLCO)*

A member inquired how the Committee is going to account for the patients who do not have a DLCO because they are on too much oxygen. A member asked how the GAP index addresses a patient who is unable to perform the pulmonary function test (PFT). The Chair noted that those patients will be on high amounts of oxygen so will get additional points in their score and the intent of collecting this information is to distinguish between interstitial lung disease (ILD) patients on the same oxygen amount. Members felt that the sickest patients would be missed and the Committee supported adding an option for “the patient cannot perform this test”. A member inquired what happens with a center that doesn’t have a test done but can do one, and members stated that it would just be missing. The Chair clarified that technically the program can enter data from the last 6 months and it would be on that update schedule.

### *Assisted ventilation*

A member suggested adding venoarterial (VA) and venovenous (VV) ECMO.

### *Requires Supplemental Oxygen (O2)*

A member mentioned that L/min and percent for high flow can both be entered. A member stated that a patient who is on 40% and has a high minute ventilation which requires an increase in liter flow is different than a patient who is at 100% on 50 liters. The Chair mentioned that the conversions for liters to fraction of inspired oxygen (FiO2) are not exact. Members felt that both the liters and the percent needs to be captured (i.e. 30 liters at 100%).

Members also reviewed a policy change for O2. Staff explained that the policy change states that members should report the correct number for O2, but anything over 26.33 L/min needed at rest is going to be treated as 26.33 L/min needed at rest. Members suggested high flow devices should base their score off of FiO2 and it was asked if it would disadvantage those candidates if their percent is 30 but they are on 50 liters. A member mentioned that the Committee needs to be thinking of what the predictor is for waitlist survival and it’s based on a patient’s FiO2, but FiO2 cannot be calculated exactly by just using a nasal cannula. It comes down to how effectively oxygen is being delivered.

A member agreed that they report FiO2; however, they think the system is working how it is supposed to right now. A member mentioned that this reporting is meant to be a transition until the Committee has more data.

### *Six Minute Walk (6MW) Distance*

A member asked if 6MW was defined as part of this project and the Chair stated that it was not since there are no sufficient definitions available. They added that the ATS definition was basically that the patient walks off of oxygen until they collapse and there is no oxygen titration. The Vice Chair added that this variable will continue to be inconsistent until it is appropriately defined. A member asked why the Committee could not take that on since this data is important. A member asked why this variable is added in Waitlist and the Chair clarified that it is thought that the shorter the 6MW distance, the higher the candidate's waitlist mortality. A member mentioned that this should be addressed, but recognized that it would be difficult to define. They also noted that a problem with the LAS is that a candidate gets more points if they are on oxygen at rest than they do with oxygen at exertion. The difference in program procedures hinders patients since programs who allow for oxygen usage during 6MW will have longer walk distances. A member stated that programs will follow the ATS definition where a patient is on five liters at rest, but then they will perform the test on zero liters. Members agreed that it is very random as to how programs perform a 6MW test and the Committee should discuss this further. A member suggested that whatever O2 a patient requires to walk on a flat surface should be used when performing the test since the test is really supposed to be a marker of patient frailty. A member added that a program should use the same oxygen amount that is indicated for "with exercise" when performing the 6MW and that the test is performed on a flat surface.

A member added that not using oxygen or using "at rest" oxygen amounts is not truly reflecting the ability of the patient. A member noted that their program titrates the oxygen up as the patient needs to complete the test and the Chair stated that a patient that starts and ends on four liters is different than one who starts on four liters and ends on 15 liters. Staff asked if it is important to capture start and end liter values and members agreed that would be needed. Other members suggested starting at one value and leaving it constant, but SRTR added that having the start and end changes would provide better information. Another member said their program does two walks, a titration walk to get those values and then a 6MW. The Committee agreed that standardization is needed and suggested a Subcommittee to address this issue. It was noted that frailty and oxygen requirement are two different things, and while oxygen may be more important they are both important. The Vice Chair stated that the use of frailty should be avoided and endurance should be used. The suggested interim definition for 6MW would be the total exertional distance on a flat surface.

### *Remove from Waitlist*

A member stated that they look at post-bronchodilator as an indicator for COPD. Members stated that if they are managing COPD it is not as relevant and there is no reversibility when they are at the point of listing. SRTR noted that they assume that if a patient is waitlisted, then the program feels that there is a survival advantage from transplant.

### *Add to Transplant Candidate Registration (TCR) Form*

Staff inquired if this information should go on the TCR. A member felt that having to track that information would be a huge burden for coordinators and entering historic data across forms opens things up for error. A member stated that a delta change is not super important since the severity of disease is continuously evaluated post-listing. A member inquired if the proposed data collection in Waitlist is not capturing the sickness enough and if that is why it needs to be captured again on the TCR. A member felt this was most appropriate for CF which is such small cohort of the candidates currently. A member also mentioned that ILD patients will have other parameters to signify their sickness. A member stated the CF and ILD patients may be who centers should be requesting exceptions for. A member

stated that, in their experience as a coordinator, they already list previous PFTs in the listing to document a patient's sickness. A member suggested opening the BNP data for anyone to enter.

The Committee agreed to look at previous PFT data only in the same way current serial data is collected, in Waitlist not the TCR.

There was no further discussion.

## **7. Brainstorm and Open Forum**

The Committee brainstormed areas and projects that they think they could improve upon. The following ideas were mentioned:

- ECMO bridging information
  - Knowing L/min so the Committee has a sense of the kind of support
  - A lot of ambiguity in practice, as well as VA and VV ECMO
- 6MW Standardization
- LAS Exception
  - Multiple listing sites, does the score go with the candidate?
- Pediatric ABOi Lung Criteria
- Review of Data Collection Forms
  - Specifically, some fields on the pediatric forms (i.e., cognitive development)
  - Retire variables with a significant amount of missing data
- Adding High Flow Calculation in the LAS and composite allocation score (CAS)

### Summary of discussion:

#### *ECMO bridging information*

A member mentioned that the Committee should review the ECMO data and didn't think that there was a huge push to collect the information about a patient's flow because it wasn't thought that was predictive.

A member mentioned that, with the current data, there's an association between ECMO bridging and mortality and significant effects between ECMO salvage and mortality. The member stated they are trying to highlight the gaming. For example, how does the Committee prevent cannulating at 100 percent O2 but the patient is on one liter? Members stated that hopefully no one is putting patients on ECMO just to game the system, especially because there are other risks.

A member mentioned that the only prognostic indicators in the ECMO data is the ability of the patient to be awake and participating. The member mentioned that a patient being on a dual lumen doesn't make them any more likely to ambulate.

A member also noted that the Committee may want to look at conversion and modality, since conversion is usually a bad prognostic indicator.

#### *Review of Data Collection Forms*

A member inquired if risk adjustment is in the SRTR data. For example, when looking at the risk modeling for centers, being on ECMO does not increase the risk of post-transplant mortality. SRTR explained that the retrospective program specific reports adjust for candidate, donor, institution, and surgical variables as much as can be gathered; however, at allocation the donor, institution and surgical variables are not known.

A member stated that they believe if the data is entered then it can be used for the program specific reports.

#### **8. Next Steps and Closing Comments**

The Committee recognized those members rolling off of the Committee and thanked them for all of their contributions.

#### **Upcoming Meeting**

- June 16, 2022

## Attendance

- **Committee Members**
  - Erika Lease, Chair
  - Marie Budev, Vice Chair
  - John Reynolds
  - Julia Klesney-Tait
  - Whitney Brown
  - Errol Bush
  - Cynthia Gries
  - Denny Lyu
  - Nirmal Sharma
  - Marc Schecter
  - Jasleen Kukreja
  - Kelly Willenberg
  - Pablo Sanchez
  - Karen Lord
  - Staci Carter
  - Soma Jyothula
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Katie Audette
  - David Schladt
  - Maryam Valapour
  - Nick Wood
- **UNOS Staff**
  - Elizabeth Miller
  - Krissy Laurie
  - Sara Rose Wells
  - Darby Harris
  - Tatenda Mupfudze
  - Susan Tlusty
  - Tamika Watkins
  - Carson Yost
- **Other Attendees**
  - Matt Hartwig
  - Lara Schaheen
  - Stephen Huddleston
  - Serina Patrick
  - Edward Cantu