

Notice of OPTN Policy Changes

Incorporating COVID-19 Related Organ Failure In Candidate Listings

Sponsoring Committee:	OPTN Lung Transplantation Committee
Policies Affected:	10.1.F.i Lung Disease Diagnosis Groups
Public Comment:	August 31, 2020 – October 1, 2020
Board Approved:	October 8, 2020
Effective Date:	October 28, 2020

Purpose of Policy Changes

Lung transplantation has emerged as a treatment option for some patients with severe lung and heart damage resulting from COVID-19. The OPTN does not currently have a method for identifying candidate listings for COVID-19 related organ failure. Although some lung patients are known to have been transplanted in the United States, it is currently unknown whether other candidates have been listed or transplanted as a result of lung or heart disease caused by COVID-19.

These changes establish standard diagnoses for listing lung and heart candidates due to damage caused by COVID-19. They include a policy change for lung since diagnoses are included in lung allocation policy. Ultimately, the changes will allow identification of trends in listing candidates for COVID-19, and potentially even more accurate inclusion in future updates to allocation policies.

Proposal History

The Lung Committee solicited feedback on the proposal during a special public comment period August 31, 2020 through October 1, 2020. One question the Lung Committee asked was whether similar diagnosis options were needed for organs other than lung. Responses, including those from the OPTN Heart Transplantation Committee, favored adding similar diagnosis codes for heart candidates. The Lung Committee included those changes in the final proposal, and two new and one revised diagnosis code will be implemented for heart candidates at the same time as the policy and system changes for lung.

Summary of Changes

The following diagnoses will be added as options for heart and lung candidates:

Lung Candidates

- COVID-19: acute respiratory distress syndrome (ARDS)
- COVID-19: pulmonary fibrosis

Heart Candidates

- COVID-19: dilated myopathy: active myocarditis
- COVID-19: dilated myopathy: history of myocarditis

- Dilated Myopathy: Viral changed to Dilated Myopathy: Viral (not COVID-19)

Lung candidates listed with the new diagnoses will be included in diagnosis group D.

Implementation

The proposal will require programming changes in UNetSM.

Transplant programs will have new diagnosis codes available for lung candidates and new diagnosis codes and an update to an existing code available for heart candidates.

Affected Policy Language

New language is underlined (example) and language that is deleted is struck through (~~example~~).

10.1.F.i Lung Disease Diagnosis Groups

The LAS calculation uses diagnosis Groups A, B, C, and D as listed below.

Group A

A candidate is in Group A if the candidate has *any* of the following diagnoses:

- Allergic bronchopulmonary aspergillosis
- Alpha-1 antitrypsin deficiency
- Bronchiectasis
- Bronchopulmonary dysplasia
- Chronic obstructive pulmonary disease/emphysema
- Ehlers-Danlos syndrome
- Granulomatous lung disease
- Inhalation burns/trauma
- Kartagener's syndrome
- Lymphangioleiomyomatosis
- Obstructive lung disease
- Primary ciliary dyskinesia;
- Sarcoidosis with mean pulmonary artery pressure of 30 mm Hg or less
- Tuberos sclerosis
- Wegener's granuloma – bronchiectasis

Group B

A candidate is in Group B if the candidate has any of the following diagnoses:

- Congenital malformation
- CREST – pulmonary hypertension
- Eisenmenger's syndrome: atrial septal defect (ASD)
- Eisenmenger's syndrome: multi-congenital anomalies
- Eisenmenger's syndrome: other specify

- Eisenmenger's syndrome: patent ductus arteriosus (PDA)
- Eisenmenger's syndrome: ventricular septal defect (VSD)
- Portopulmonary hypertension
- Primary pulmonary hypertension/pulmonary arterial hypertension
- Pulmonary capillary hemangiomatosis
- Pulmonary telangiectasia – pulmonary hypertension
- Pulmonary thromboembolic disease
- Pulmonary vascular disease
- Pulmonary veno-occlusive disease
- Pulmonic stenosis
- Right hypoplastic lung
- Scleroderma – pulmonary hypertension
- Secondary pulmonary hypertension
- Thromboembolic pulmonary hypertension

Group C

A candidate is in Group C if the candidate has *any* of the following diagnoses:

- Common variable immune deficiency
- Cystic fibrosis
- Fibrocavitary lung disease
- Hypogammaglobulinemia
- Schwachman-Diamond syndrome

Group D

A candidate is in Group D if the candidate has *any* of the following diagnoses:

- ABCA3 transporter mutation
- Alveolar proteinosis
- Amyloidosis
- Acute respiratory distress syndrome or pneumonia
- Bronchioloalveolar carcinoma (BAC)
- Carcinoid tumorlets
- Chronic pneumonitis of infancy
- Constrictive bronchiolitis
- COVID-19: acute respiratory distress syndrome
- COVID-19: pulmonary fibrosis
- CREST – Restrictive
- Eosinophilic granuloma
- Fibrosing Mediastinitis
- Graft versus host disease (GVHD)
- Hermansky Pudlak syndrome
- Hypersensitivity pneumonitis
- Idiopathic interstitial pneumonia, with at least one or more of the following disease entities:
 - Acute interstitial pneumonia

- Cryptogenic organizing pneumonia/Bronchiolitis obliterans with organizing pneumonia (BOOP)
- Desquamative interstitial pneumonia
- Idiopathic pulmonary fibrosis (IPF)
- Nonspecific interstitial pneumonia
- Lymphocytic interstitial pneumonia (LIP)
- Respiratory bronchiolitis-associated interstitial lung disease
- Idiopathic pulmonary hemosiderosis
- Lung retransplant or graft failure: acute rejection
- Lung retransplant or graft failure: non-specific
- Lung retransplant or graft failure: obliterative bronchiolitis-obstructive
- Lung retransplant or graft failure: obliterative bronchiolitis-restrictive
- Lung retransplant or graft failure: obstructive
- Lung retransplant or graft failure: other specify
- Lung retransplant or graft failure: primary graft failure
- Lung retransplant or graft failure: restrictive
- Lupus
- Mixed connective tissue disease
- Obliterative bronchiolitis: non-retransplant
- Occupational lung disease: other specify
- Paraneoplastic pemphigus associated Castleman's disease
- Polymyositis
- Pulmonary fibrosis: other specify cause
- Pulmonary hyalinizing granuloma
- Pulmonary lymphangiectasia (PL)
- Pulmonary telangiectasia – restrictive
- Rheumatoid disease
- Sarcoidosis with mean pulmonary artery pressure higher than 30 mm Hg
- Scleroderma – restrictive
- Secondary pulmonary fibrosis: (specify cause)
- Silicosis
- Sjogren's syndrome
- Surfactant protein B mutation
- Surfactant protein C mutation
- Teratoma
- Wegener's granuloma – restrictive