Interstitial Lung Disease Program

INDIVIDUAL CARE PLAN

UNDERSTANDING MY DISEASE
TREATMENT
EDUCATION

#1 Respiratory Hospital in the nation, since 1998
U.S. News & World Report

National Jewish Health
Science Transforming Life
Welcome to the Interstitial Lung Disease Program at National Jewish Health. Our goal is to help people with Interstitial Lung Disease to manage their disease and improve the quality of their lives. We are here to partner with you to manage your care.

At each visit, you will meet with physicians who are experts in the field of Interstitial Lung Disease. A comprehensive individual plan will be created for you to help manage your lung disease. This plan will consist of testing, education and possible medical therapies. We have a multidisciplinary team approach to address any medical and social issues that may impact your quality of life.

This binder is provided to you to help explain your plan of care and more about Interstitial Lung Disease. Please feel free to add any additional information provided to you and bring this to each appointment.

Please don’t hesitate to ask any questions and we look forward to participating in your healthcare.

Sincerely,

National Jewish Health
Interstitial Lung Disease Program

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Sarah Weddington, Medical Assistant, ILD Program
Laurie McIntyre, Administrative Assistant
When to Contact your Health Care Provider

If you are having increased shortness of breath or chest pain call 911 to have an ambulance take you to the nearest emergency room.

If you are experiencing any of the symptoms below please contact your physician via the National Jewish Health Adult Triage Nurse at 303-398-1355, option 4. They are available Monday through Friday, 8am-5pm MST. You may also contact your physician at NJHealth.org through My National Jewish Health online accounts.

- You are more short of breath than usual with rest or activity
- You have increased oxygen requirements
- Coughing up yellow, green, brown or blood tinged sputum
- Fevers or chills, nausea and vomiting

Please do not hesitate to call if you have any concerns on how you are feeling or develop new symptoms.

My Doctor's Name is: ___________________________________

Scheduling:
If you are an out of state patient to schedule appointments please call
1-877-225-5654
If you are a local patient to schedule appointments please call general scheduling at:
303-398-1355 option 4

Medical Questions:
To speak with a nurse or your doctor, or for prescription refills, please call the Telephone Triage Nurses at:
303-398-1355 option 4
Our fax number is 303-270-2130

Medical Records:
For any questions pertaining to medical records please contact our Release of Information Department at:
303-398-1256

Social Workers:
For any questions pertaining to oxygen or social issues please call Elizabeth Langhoff at 303-270-2743 or Courtney Trout 303-398-1397.
Glossary of Commonly Used Terms

**Agitated Saline Echocardiogram** - Ultrasound of the heart using saline (sterile salt water) that can show the flow of blood through the heart and enhance the pictures of the heart.

**Alveoli** - Tiny, thin-walled air sac at the end of the bronchiole branches where oxygen crosses the capillaries into the bloodstream and carbon dioxide crosses from the bloodstream into the alveoli to be exhaled.

**Arterial Blood Gas** - This is a blood sample test ordered by your physician to evaluate measurements of oxygen level, carbon dioxide (effectiveness of respiration), and several other parameters. Generally, it is indicated when your physician needs to evaluate the effectiveness of your breathing.

**Aspiration** - Inhalation of material such as liquid, food, secretions or stomach contents into the lungs.

**Bipap** - A machine which administers air under pressure via a mask to keep the airways open and unobstructed.

**Bronchi** - The larger air passages of the lungs that are main branches of the trachea (windpipe).

**Bronchioles** - The tiny branches of air tubes within the lungs that are the continuation of bronchi and connect to the alveoli.

**Bronchiolitis Obliterans** - Inflammation of the bronchioles with obstruction by fibrous granulation tissue or bronchial exudate. It may follow inhalation of irritating gases or foreign bodies and it complicates pneumonia.

**Bronchodilator** - A medication that relaxes the smooth muscles of the bronchi and opens (widens) constricted (narrowed) airways.

**Bronchoscopy** - A procedure that allows the doctor to look inside the airways in the lungs. The bronchoscopy can be videotaped to look at later. Your doctor may also do a lavage, which involves putting a small amount of fluid into the airways. The fluid is then pulled out. The fluid contains cells from the airways of your lungs. A biopsy of the airway may also be done. During a biopsy a small amount of the tissue is taken from the lining of the lung. The cells and tissue can be studied closely to help determine your diagnosis and the best treatment for you.

**Bronchus** - Either of the two main branches of the airway (right and left) that connect the trachea (windpipe) with the lungs.
Capillary- Tiny blood vessels.

Carbon Dioxide (CO2)-This gas is produced by the tissues as a waste product, and carried in the blood to the lungs to be exhaled. In the lungs CO2 is exchanged for oxygen (O2).

Cardiopulmonary Exercise Test- Evaluates the ability of your heart and lungs to provide oxygen and remove carbon dioxide from the bloodstream before, during and after you exercise.

Computerized Axial Tomography Scan (CAT or CT Scan)-An x-ray procedure that uses a computer to produce a series of three dimensional images of the body and it's organs.

Diffusing Capacity for Carbon Monoxide(DLCO)- This test measures how well gases (oxygen) move through the lung and into the bloodstream.

Dyspnea- Shortness of breath or hard time breathing.

Echocardiogram- An echocardiogram is an ultrasound of the heart. The ultrasound shows the structures and functions of the heart muscle and heart valves from different angles. It does this by using sound waves.

Exertional Dyspnea- Shortness of breath with activity.

FEV1/FVC-The amount of air that can be forcibly breathed out in one second (FEV1) divided by the total amount of air that can be breathed out (forced vital capacity or FVC).

Forced Vital Capacity (FVC)-After taking in as deep a breath as possible, the air is breathed out as forcibly as possible until no more can be breathed out. This gives an indication of the size of the lungs, how compliant (elastic) they are and how well the air passages open and close.

Hemoptysis- Coughing or spitting up blood.

Hypoxemia- Inadequate oxygenation of the blood (saturation of oxygen (SaO2) is less than 85%). Symptoms of hypoxemia include fast heart rate, anxiety, agitation forgetfulness, inability to concentrate, and changes in levels of consciousness.

Hypoxia- Oxygen is needed by all tissues in the body to do the work each is designed to do. Hypoxia exists when an inadequate or deficient amount of oxygen reaches the tissues.

Intubation- Placing a tube in the trachea to assist with breathing.

Obstructive Lung Disease- Lung disease that limits air flow making it difficult to exhale air from the lungs.
**Osteopenia**- A decrease in bone mineral density that can lead to osteoporosis.

**Osteoporosis**- Loss of calcium in the bones.

**Oxygen Saturation**- A measure of how much oxygen the blood is carrying.

**Palliative Care**- Palliative care refers to medical care provided by doctors and other members of the healthcare team that is aimed at providing maximum comfort and relief of disease symptoms for a patient. The focus of care is no longer cure, disease control, or prolonging life but instead to assist the patient and family in achieving the best quality of life for the remainder of the patient's life.

**Pleura**- The thin serous membrane enveloping the lungs and lining the thoracic (chest) cavity.

**Pleural Cavity**- The chest cavity. It houses the heart and lungs.

**Pleural Effusion**- Presence of fluid in the pleural cavity. It is a sign of disease and not a diagnosis in itself.

**Pneumothorax**- An accumulation of air or gas in the pleural space, which may occur spontaneously or as a result of trauma or a pathological process and results in partial or complete collapse of the lung. The air needs to be drained from the space it occupies. Usually, a tube, called a chest tube, is inserted into the space and left in place until the air is expelled and the lung re-expands.

**Pulmonary Function Test (PFT)**- Pulmonary function testing measures how well you are breathing. They include spirometry, lung volumes and diffusing capacity.

**Pulmonary Nodules** - A round or oval-shaped, small abnormality in the lungs.

**Pulmonary Rehabilitation**- An exercise program for people with chronic lung disease to help increase strength and endurance along with pulmonary function.

**Pulse Oximeter**- Oximetry is a procedure, which measures the oxygen level in your blood, without having to take a blood sample, on a continuous basis. A painless clip is placed on your fingertip or ear lobe, while the reading is on a device attached by a wire.

**PO2 or PaO2**- Partial pressure of oxygen.

**PCO or PaCO2**- Partial pressure of carbon dioxide.

**Residual volume (RV)**- Residual Volume (RV), is the volume of air that remains in the lungs after exhaling out as much air as possible.
**Restrictive Lung Disease**- Lung disease that restricts the lungs from fully expanding.

**Spirometry**- A simple test to measure how much (volume) and how fast (flow) you can move air into and out of your lungs.

**Thorascopic Surgery**- This is often performed with the use of a thoracoscope that allows the surgeon to biopsy multiple areas of one lung through a few very small incisions. Also known as a VATS (Video – Assisted Thoracic Surgery).

**Thoracentesis** - The doctor inserts a needle or a thin, hollow, plastic tube through the ribs in the back of your chest into your chest wall. A syringe is attached to draw fluid out of your chest.

**Total Lung Capacity**- Total Lung Capacity (TLC) is the total volume of gas (air) in the lungs after a maximal voluntary inspiration.

**Trachea**- The rigid tube that connects the mouth with the bronchi (windpipe).

**Transtracheal Oxygen**- Delivery of oxygen through a thin catheter placed directly in the trachea.

**Vital Capacity (VC)**- The difference between Total Lung Capacity (the total amount of air the lung can hold) and Residual Volume (the air that remains in the lung after a person has breathed out as hard as possible). It is the maximum amount of air which can be breathed out slowly after as taking as big a breath in as possible.
Resources

**National Jewish Health**  
1400 Jackson St.  
Denver, CO 80113  
Phone (303)398-1355  
www.NJHealth.org

**Pulmonary Fibrosis Foundation**  
811 West Evergreen Ave, Suite 204  
Chicago, IL 60642  
Phone (888) 733-6741 Fax (866) 587-9158  
www.pulmonaryfibrosis.org

**Coalition for Pulmonary Fibrosis**  
10866 W. Washington Blvd #343  
Culver City, CA 90232  
Phone (888) 222-8541  
info@coalitionforpf.org

**United Network for Organ Sharing (UNOS)**  
Post Office Box 2484  
Richmond, VA  23218  
Phone (804) 782-4800 Fax (804) 782-4817  
www.unos.org

**Colorado Lung Association**  
5600 Greenwood Plaza Blvd. Suite 100,  
Greenwood Village, CO 80111  
Phone (303) 388-4327 Fax (303) 377-1102  
www.lung.org/associations/states/colorado

**American Lung Association**  
1301 Pennsylvania Ave. NW, Suite 800  
Washington, DC 20004  
Phone (202) 785-3355 Fax (202) 452-1805  
www.lung.org

**National Institutes of Health (NIH)**  
9000 Rockville Pike  
Bethesda, MD 20892  
www.nih.gov  
Clinical Trials.gov  
A service of the U.S. National Institutes of Health  
www.clinicaltrials.gov

For lodging options go to our website at www.njhealth.org/patient-info/travel/lodging/.
Questions to ask my health care team…

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Journal Entries

Consider your sleep, diet, shortness of breath, exercise and medications.

Date: ______________

Things that went well today…

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Difficulties I had today…

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To make things better tomorrow, I will…

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Date: ______________

Things that went well today…

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Difficulties I had today…

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To make things better tomorrow, I will…

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