



VOLUME: 1 ISSUE: 7

Interstitial lung disease (ILD) refers to a group of diseases affecting the tissue and space around the air sacs of the lungs. Most of these diseases cause progressive scarring in this tissue. Once lung scarring occurs, it is generally irreversible. Medications may slow the damage of interstitial lung disease, but many people never regain full use of their lungs. Interstitial lung disease can be caused by long-term exposure to hazardous materials, such as asbestos. Some types of autoimmune diseases, such as rheumatoid arthritis, also can cause interstitial lung disease. In most cases, however, the causes remain unknown.

ILD NEWSLETTER: Working together to improve your quality of life

Exercise and Pulmonary Fibrosis

Exercise is recommended for patient with pulmonary fibrosis. Although exercising will not improve your pulmonary fibrosis, it improves your cardiovascular system and muscles so they don't need to work as hard to compensate for the inflammation and/or scarring in your lungs. Exercise will help to prevent deconditioning and weakness which often occurs when you are short of breath. In general slowly progressing to moderate exercise is safe and encouraged. Regardless if your disease is mild, moderate or severe some form of exercise is recommended and for those waiting on the lung transplant list exercise is mandatory. Aim to get some aerobic exercise approx. 20-30mins 3-5 times per week, and some form of strength training using light weights. Please stop and talk to your Dr. if you feel dizzy or light-headed, chest pain, visual changes or have pre-existing cardiac problems.

Hopefully now that the weather is slowly improving you may be able to enjoy the warmth and outdoors. If planning to exercise outside you may want to check on the air quality health index and avoid exercise in the extreme heat or cold.

Check air quality via this link:

<http://www.ec.gc.ca/cas-aqhi/default.asp?lang=En&n=450C1129-1>

For more information on exercise and rehabilitation, please see the excellent information on the CPFF website @ <http://cpff.ca/living-with-pf/rehab-and-exercises/>

In the News

Pulmonary Fibrosis Foundation launches PFF Patient Registry:

This comprehensive collection of data is collected from participating pulmonary fibrosis patients across the United States at participating PFF Care Center Network sites. The overall goal of the patient registry is to improve our understanding of interstitial lung diseases and ultimately lead to improved treatment and care of patients.

"The PFF Patient Registry is an important research tool that will help us unlock the mysteries of this devastating and fatal disease. People with nearly all types of PF will be able to participate, and in a secure, confidential manner," Patti Tuomey, EdD, PFF president and CEO, said in a press release. "The Foundation is so grateful to the medical teams at the PFF Care Center Network sites who are enrolling patients, and especially to patients who are participating and all of the families, friends, and donors who are endorsing this Registry."

This registry will permit researchers, through generous contribution of medical data by patients, with anonymous information to gain a better understanding of how patients are affected by pulmonary fibrosis and how they respond to different treatments. Access to this information will be the building blocks of assisting clinicians identify best practices in care and discover which treatments are best for which patients.

"Information collected through the PFF Patient Registry will help facilitate ongoing research necessary to better understand how we can help people living with multiple types of pulmonary fibrosis, including other diseases that often include PF, such as rheumatoid-arthritis associated pulmonary fibrosis," said Kevin Flaherty, MD, MS, Steering Committee Chairman, PFF Care Center Network and PFF Patient Registry. "This project provides an incredible opportunity to advance progress toward a cure for pulmonary fibrosis." There are plans in place to develop a similar registry involving our Canadian patients in the near future.

ONLINE RESOURCES:

Canadian Pulmonary Fibrosis Foundation:

<http://www.canadianpulmonaryfibrosis.ca/>

Twitter: @THE_CPF

Facebook:

Canadian Pulmonary Fibrosis Foundation: Non-Profit Organization

Pulmonary Fibrosis Foundation:

<http://www.pulmonaryfibrosis.org/home>

Twitter: @PFFORG

Facebook: Pulmonary Fibrosis

Foundation: Charity Organization

THE LUNG ASSOCIATION:

<http://www.lung.ca/>

Scleroderma Foundation:

www.scleroderma.org

SUPPORT GROUP MEETING INFORMATION:

When: Tuesday, May 24, 2016

Where: Toronto General Hospital
1st Floor Eaton South Building
(Elizabeth Street Entrance)

Conference Room 450a

Time: 1:30-3:30pm

For Who? ILD patients and caregivers

Speaker: Robert Davidson,
President of the CPFF

Topic: My diagnosis, my search for support, and establishment of CPFF.

Please RSVP to:

mandy.ettinger@uhn.ca



Palliating Symptoms

One of the goals of care in patients with pulmonary fibrosis is to prevent disease progression. Another goal of care is to reduce symptoms such as shortness of breath, chronic cough, depression and anxiety which is equally important. Treating these symptoms will allow you to reach your maximum level of wellness and improved quality of life.

Common symptoms of pulmonary fibrosis develop over time and tend to start off lightly and become severe in more advanced stages of the disease.

1. Shortness of breath
2. Breathlessness
3. Cough
4. Weight loss
5. Fatigue
6. Depression

Many respirologist and primary care physicians may already be managing these symptoms however you may also want to be referred to a symptom management specialist such as palliative care. Although there continues to be a stigma surrounding palliative care, as it can often be viewed as giving up, this is simply not true. Palliative care can help with symptom burden and in many studies has shown to prolong and improve quality of life. This care does not specifically treat pulmonary fibrosis; however it is designed to improve the quality of life for anyone dealing with a chronic illness. The individuals in a palliative care team, made up of physicians, nurses, social workers, psychologists, will work with you and your family in developing goals to improve such symptoms as breathlessness or any other distressing symptoms you may experience, your needs, expectations, hopes and fears.

Palliative care can be offered to people of every age and at any point in their illness. If you are interested in being referred or for more information, please contact your respirologist, family doctor or us in the ILD clinic.



Fundraising, Awareness and Events

Nominate your IPF Champion as a Kiss IPF goodbye Champion: The

Canadian Pulmonary Fibrosis Foundation has launched a program which invites Canadian residents to nominate Canadian healthcare providers to be recognized for their contributions to improve the lives of people living with IPF. This can be any healthcare provider who has made a positive impact on patients and caregivers through their commitments, care and ongoing work with the IPF community. For more information on this program and how to nominate your healthcare provider, please visit the Canadian pulmonary fibrosis foundation website following this direct link: <http://cpff.ca/champions/>

ORGAN DONATION

From March 30-April 30 is Organ Donation Awareness month. More than 85% of Ontarians are in favor of organ donation, however only 1 in 4 have registered their consent to donate. Visit <http://www.giftoflife.on.ca/en/> for more information.