



VOLUME: 1 ISSUE: 3

ILD NEWSLETTER: Working together to improve your quality of life

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.

TREATMENTS

OFEV™ (Nintedanib): is an anti-fibrotic agent used for the treatment of idiopathic pulmonary fibrosis (IPF) in adults. This drug has recently been approved by Health Canada. Boehringer Ingelheim announced new data and analyses for OFEV™ reinforcing its efficacy, safety and tolerability in a broad range of patients with idiopathic pulmonary fibrosis (IPF). These findings were presented at the American Thoracic Society (ATS) 2015 International Conference in Denver, United States. In studies OFEV™ has shown to slow the progression of IPF by reducing the decline in lung function. For more information please contact your Respirologist or ILD specialist.

PULMONARY REHABILITATION TIPS

A pulmonary rehabilitation program is recommended to help you achieve your highest level of functioning. This program includes education, exercise conditioning, breathing techniques, and energy saving techniques, respiratory therapy evaluation, nutritional counseling and psychosocial support.

The specific goals of pulmonary rehabilitation are to improve quality of life by: decreasing respiratory symptoms and complications, encouraging self management and control over daily functioning, improving physical conditioning and exercise performance, improving emotional well being and reducing hospitalizations.

ILD TEAM MEMBERS



Dr. Ted Marras is a staff MD in the respiratory department of the University Health Network and an assistant professor at the University of Toronto. He received his initial education at Queen's University in Kingston, where he earned his BSc and his medical degree. He then completed his postgraduate training in internal medicine and respirology, followed by his MSc (Clin Epi) at the University of Toronto. He has taken two years of clinical research training in mycobacterial diseases at the University of California, San Francisco and one month each at Stanford University and National Jewish Medical Center in Denver, Colorado. Dr. Marras' research is focused on non-tuberculous mycobacterial infections. His clinical work includes nontuberculous mycobacterial disease, TB, and interstitial lung disease.

ONLINE RESOURCES:

Canadian Pulmonary Fibrosis Foundation:

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

Twitter: @THE_CPFF

Facebook:

Canadian Pulmonary Fibrosis Foundation: Non-Profit Organization

Pulmonary Fibrosis Foundation:

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

Twitter: @PFFORG

Facebook: **Pulmonary Fibrosis Foundation: Charity Organization**

Scleroderma Foundation:

www.scleroderma.org

SUPPORT GROUP MEETING INFORMATION:

When: Tuesday, Sept. 22, 2015

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: Dr. Andrew Youn –
Pharmacological Treatments for IPF

Please RSVP to:

mandy.ettinger@uhn.ca



BETTER BREATHING TECHNIQUES:

Short of Breath?

- STOP what you are doing and rest in a comfortable place
- LOWER your head and shoulders & try to relax
- Breathe in and out through your mouth
- Begin to breathe in through your nose and out through your mouth
- STAY in this position for 5-10 minutes until your breathing returns to YOUR normal
- Use pursed lip breathing or diaphragmatic breathing IF you find them helpful (not all ILD patients do).

Positions for Shortness of Breath

SITTING

- Rest your feet flat on the floor
- Lean your chest forward slightly
- Rest your elbows on your knees or rest your chin in your hands
- OR:
- Rest your arms on a table, rest your head on your forearms or some pillows
- Relax your neck & shoulders

STANDING:

Position 1:

- Stand with your feet shoulder width apart
- Lean your hips against a wall
- Rest your hands on your thighs
- Relax your shoulders, leaning forward slightly and dangling your arms in front of you

Position 2

- Rest your elbows or hands on a piece of furniture just below shoulder height
- Relax your neck, resting your head on your forearms
- Relax your shoulders
- AVOID `grabbing` onto the furniture as this can overwork your muscles and increase your shortness of breath if held for too long!

(Pictures and descriptions available if needed, just send me an email!)

PULMONARY FIBROSIS EVENTS

CPFF Annual IPF Awareness Day at Queen's Park - September 15th

CPFF's IPF Awareness Day at Queen's Park is a chance for Ontario-based IPF patients and their families to continue to raise awareness of IPF among legislators and policy-makers, and to promote the message that IPF patients should have access to all approved treatments for IPF

We're looking for interested patients, caregivers, family members and anyone else who is affected by IPF to join us. If you are interested in participating in any or all of these activities please let us know as soon as possible.

To ensure we get a meeting with your local MPP, we need to give ample notice to their offices. If you wish to meet with government officials please ensure you provide your mailing address in your email so that we can determine your riding.

Andrew Retfalvi from Global Public Affairs is coordinating our efforts that day; please contact Andrew at aretfalvi@globalpublic.com or call him at 416.886.1255 to let him know that you'll be attending, or if you have any questions or concerns.

SEPTEMBER IS PULMONARY FIBROSIS AWARENESS MONTH!

Participate in "kiss IPF goodbye" and visit:
<http://www.canadianpulmonaryfibrosis.ca/kiss-ipf-goodbye/>

Or Visit globalpfawareness.org to get involved.

SCOTIABANK TORONTO WATERFRONT MARATHON – SUNDAY, OCTOBER 18, 2015:

To register for this event, please go to:
<http://www.torontowaterfrontmarathon.com/en/charity/cpff.htm>

Upcoming Conference: PFF Summit 2015, November 12-14, Washington DC www.pffsummit.org.