



VOLUME: 1 ISSUE: 1

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.

TEST INFORMATION

WHY DO I HAVE PFT's EACH TIME I VISIT?

Pulmonary function tests (PFT's) are breathing tests that are ordered by a physician and used in the assessment and management of your lung disease. It helps us to:

- Find the cause of shortness of breath
- Assess the effect of medication
- Monitor disease progress



PULMONARY REHABILITATION TIPS



Pulmonary rehabilitation programs work with adults who have chronic lung disease such as ILD to improve their ability to care for themselves. Patients learn skills to stay healthy, such as stopping smoking, exercise, coping better, proper nutrition and ways to better control their fatigue and shortness of breath. Stay tune for more tips in this section.

Let us know if you are interested in one of these programs!

ILD TEAM MEMBERS

Dr. Shane Shapera attended medical school and completed his internal medicine residency at the University of Toronto. He was the chief medical resident at the Toronto Western Hospital before starting his sub-specialty training in Respiriology at U of T. He was the 2009 recipient of the Cameron C. Gray fellowship and studied interstitial lung diseases during that year. He is now the director of the ILD clinic and also an assistant professor at U of T. He has a research interest in assessing and optimizing the safety of lung biopsy in ILD.



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**

1st SUPPORT GROUP MEETING INFORMATION:

When: Tuesday, May 26, 2015

Where: Toronto General Hospital
1st Floor Eaton South Building
(Elizabeth Street Entrance)
Conference Room 450a

Time: 1:00-3:00pm

For Who? ILD patients and caregivers

Speakers: Meeran Manji, RN CRE, Pulmonary Rehabilitation Coordinator, TWH
Barbara Barr, IPF patient advocate and ambassador

Please RSVP to:

mandy.ettinger@uhn.ca



MAINTAINING YOUR HEALTH:

The doctors and nurse in the ILD clinic will help you manage your disease; however remember you are the most important advocate in your treatment plan. Here are some tips from the Pulmonary Fibrosis Foundation to help maximize your care and take control of your health (<http://www.pulmonaryfibrosis.org/life-with-pf/maintaining-your-health>).

Speak up for yourself. If you have any concerns with your treatment or do not understand something about your disease, it is essential that you talk to your care providers. They want to make sure that you are able to maintain your health and will assist you with these issues.

Be prepared for your visits. Bring a list of your questions or concerns to each visit. Being prepared goes a long way in communicating with your providers – you cannot assist in the decision making process if you do not understand the factors involved.

Take notes during your visits. You will likely receive a significant amount of information during your health care visits and this can be overwhelming. Do not be afraid to take notes to help you remember important treatment issues later on.

Let your family and friends help. Emotional support is very important to maintaining your health. This is especially true if you are trying to modify your lifestyle. Quitting smoking, exercising more, or changing your diet is difficult; let those who care about you help you accomplish your goals. Do not be afraid to bring people who support you to your health appointments.

Stay informed. Continue to learn about PF. The more you know, the better you will be able to manage your disease and recognize when you need to access health services. Be advised that there is misinformation on the internet; to ensure your safety, make sure you access reliable sources of information, such as advocacy groups and respected scientific and medical sources.

CURRENT RESEARCH

Research is a key component of any ILD program and our clinic is currently actively involved in clinical trials.

If you are interested in participating in a research study or would like more information regarding our clinical trials program, please contact Judy at UHN: 416-581-8586.

EVENTS IN THE GTA

“A Breath of Spring” – 6th Annual Spring Gala: This is a fundraising event with a live and silent auction along with raffles and door prizes and dancing to great music.

When: Saturday, May 2, 2015.

Where: Le Parc Banquet Hall on Leslie at Highway 7 in Markham. For more information visit:

<http://www.canadianpulmonaryfibrosis.ca/whats-happening/events/annual-spring-gala/>

NEWS FROM CPFF: CPFF is again offering the 'Take a Breather' Caregiver Recognition Program for 2015. You can read about the 2014 program at <http://www.canadianpulmonaryfibrosis.ca/get-involved/take-a-breather-caregiver-recognition-program/>.