



VOLUME: 1 ISSUE: 6

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.

**WEATHER AND YOUR LUNGS:
TIPS FROM AMERICAN LUNG ASSOCIATION**

Find yourself asking “What’s the weather going to be today?” This can often be a question with greater implications for patients with a chronic lung disease. Ranges in weather from cold, wind, hot and humid can each provoke lung symptoms. Different weather conditions affect people differently. You can’t predict the weather, but you can be aware and monitor. If you know what makes your symptoms worse you can identify your triggers before going outside. Make sure to check the weather forecast daily to be prepared. This way you can make small adjustments to improve your day.

For example: if it is cold outside, think about loosely wrapping a scarf around your nose and mouth to warm the air before it enters your lungs. Breathe in through your nose and out through your mouth. If it is humid outside plan to stay in areas which are air conditioned or possibly install air conditioning in your home if you are able.

Below this link to learn more about the ILD clinic at TGH:
http://www.uhn.ca/MCC/PatientsFamilies/Clinics_Tests/Interstitial_LungDisease_Clinic

In the News

WHEN I THINK OF IPF, I THINK OF...
 Over 500 people from across the world were asked what it feels like to be affected by Idiopathic Pulmonary Fibrosis (IPF). This is what they said*:

FEELINGS AT DIAGNOSIS 49% FELT WORRIED "I wonder what the future holds" 45% FELT AFRAID "I found out that IPF is an incurable disease"	WHEN I THINK OF IPF, I THINK OF... 1 in 5 Hope for the future through new and effective treatments 1 in 3 Breathlessness
THE ROLE OF PATIENT GROUPS 42% said they make them feel less isolated & provide access to important information	HARDEST THING LIVING WITH IPF... 23% "Not being able to do the things you used to do before you had IPF" 18% "Knowing that IPF is a fatal disease that has no cure"
EMOTIONS FELT LIVING WITH IPF HOPEFUL, WORRIED, AFRAID, FRUSTRATED, ANXIOUS, HELPLESS, DETERMINED, TIRED, RESIGNED	PLANS FOR THE FUTURE 39% Would enjoy spending time with family 21% Would travel or go on holiday

The results of this international survey are launched on Rare Disease Day 2016 to recognise the crucial role that patients play in voicing their needs. For more information on IPF and the survey results please visit www.lifewithipf.com. *Data on file, Boehringer Ingelheim International GmbH. When I think of IPF, I think of... Global Patient Poll 2015.

This photo demonstrates the results from a published survey by Boehringer Ingelheim. The survey included 500 people living with IPF from more than 20 countries. This survey was interested in the emotional impact of Idiopathic Pulmonary Fibrosis. If you would like more information please visit this website to view the survey in more detail http://www.boehringer-ingelheim.com/news/news_releases/press_releases/2016/29_february_2016_ipf.html

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, March 22, 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

Speakers: Lana Biro, RRT, Certified Respiratory Educator Ontario Lung Association

Topic: What can the Ontario Lung Association do for me?

Please RSVP to:

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LOOKING TO THE INTERNET? BEWARE, NOT ALL INTERNET SOURCES ARE EQUAL!

There is a recently published article in the American Journal of Respiratory and Critical Care Medicine regarding the accuracy and reliability of internet resources on information for IPF. Two authors of this research are from the TGH ILD clinic, Dr. Jolene Fisher and Dr. Shane Shapera. The goal of this research was to determine the readability, content, bias and quality of online resources for IPF. The authors entered a search into Google®, Yahoo®, and Bing® with the words “idiopathic pulmonary fibrosis” and analyzed the first 200 hits.

The results after analyzing these websites:

- Half of the websites were written at or above a grade 12 reading level.
- More scientific information was available on websites from academic/governmental organizations and foundations or advocacy organizations compared to personal sites (blogs).
- Most websites provided incomplete and/or inaccurate information.
- Treatments that were either harmful and/or not helpful for IPF were described in 48% of websites.
- Azathioprine and corticosteroids were discussed as potential treatments of IPF in many of the websites, despite scientific evidence showing that these treatments are harmful.
- Scores of quality of these websites were poor in all site types, but worse in news/media reports and personal commentary (blogs) sites when compared to scientific sites and foundation/advocacy organizations.

The study researchers concluded “Patient directed online information on IPF is frequently incomplete, inaccurate, and outdated”. At present there is no reliable method for you as a patient or caregiver to identify which sites are providing appropriate information on IPF. This demonstrates a significant barrier to patient education and the need for higher standards among those who create these websites and staying up to date with advances in medicine. You should always beware and talk with your specialist or respirologist about what you read on the internet. If you would like more information on this study, feel free to contact me.

Fundraising and Awareness

Feb 29 was Rare Disease Day – visit this website to see what is being done with rare disease and advocating for patients and families affected:
<http://www.rarediseaseday.org/>

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.