

## INFORMATION SHEET

Hamilton Integrated

NOV 18 2013

Research Ethics Board



Dear Research Participant,

At the Firestone Institute for Respiratory Health (FIRH), St. Joseph's Healthcare Hamilton, our main goal is to provide our patients with the best treatment available. We are engaged in research activities to better understand how lung diseases develop, and to find better treatment options for our patients. We want to invite you to learn more about our research, and to participate in our studies. If you register for the "Pulmonary Research Registry (PURR)", we can inform you about upcoming studies you might qualify for. You can then decide whether or not you wish to participate. Patients as well as healthy volunteers are welcome to register for PURR.

**If you volunteer to be part of the Pulmonary Research Registry (PURR), we will ask you to do the following things:**

- **Agree to the collection of your contact information and personal health information from the attached "Registry Form" and from your FIRH health record (if applicable)**
- **Agree to your contact and personal health information being kept in the registry**
- **Agree to being contacted by a researcher about participation in future studies**

There may be no medical benefits to you for taking part in this registry. However, with your assistance as we conduct research studies, we will hopefully find better treatments in the future. If you choose to participate, you can withdraw at any time and have your data removed from the registry. You can also choose not to participate, and this will in no way affect the quality of care you receive at this institution.

## CONFIDENTIALITY STATEMENT

Your data will not be shared with anyone without your consent or as required by law. By having your personal health information added to a research registry there is the potential for a breach of confidentiality. Every effort will be taken to ensure that your information is kept private. Only the research team will have direct access to the registry. Only your contact information will be shared with the study co-ordinators and physicians, who might contact you about a specific study. The research team, the study co-ordinators and physicians have all signed a confidentiality agreement. Your data will be securely stored on a computer located in the research office.

All research studies that will be conducted using the registry information will be approved by the Hamilton Integrated Research Ethics Board. For the purposes of ensuring the proper monitoring of the research registry, it is possible that a member of the Hamilton Integrated Research Ethics Board may consult your research data and medical records. By signing this consent form, you or your legally acceptable representative, authorize such access.

## CONTACT US

If you have any questions, please contact the PURR Research Office:

Phone: 905-522-1155 ext 32722

E-mail: [purr@stjoes.ca](mailto:purr@stjoes.ca)

For further information please visit our website at [www.purr-at-firh.ca](http://www.purr-at-firh.ca)



If you have any questions regarding your rights as a research participant and privacy laws, you may contact the Office of the Chair of the Hamilton Integrated Research Ethics Board at 905-521-2100 ext 42013.

**If you wish to register for PURR, please complete the attached green forms (“Consent Form” and “Registry Form”), and drop them in a “PURR” mailbox in the FIRH waiting area, or mail them back to us using the provided prepaid envelope.**

**This white information sheet (including a copy of the “Consent Form”) is for you to keep for your records.**

*Thank you very much!*

*Your FIRH research team.*