

## Ontario Health Study: Our Commitment to You

### *Dear Participant,*

Thank you for your interest in the *Ontario Health Study*. Many breakthroughs in health research have come about because people like you took time out of their busy schedules to take part in a research study.

The team at the *Ontario Health Study* knows that the most important part of this study is our relationship with those who choose to participate.

I would like to reassure you that any information you provide to the *Ontario Health Study* is strictly confidential. We have worked hard to make sure that the information and samples you provide remain secure and private. The information you give us is very valuable and we take our commitment to protecting your rights and privacy very seriously.

The protection of your personal health information is governed by law under the *Ontario Personal Health Information Protection Act*. This *Act* sets out rules that must be followed when collecting, using or sharing personal health information for research purposes. From the time you arrive at the Study Centre, all of your responses, physical measurements and samples will be identified by a unique code.

To protect your privacy, the contact information (e.g. name, telephone number, address) that we used to invite you to participate in the *Study* will be stored separately and securely from your medical information.

The *Ontario Health Study* is a world-class study. Scientists in Ontario, as well as collaborators in

other provinces and countries, will be interested in examining the information and samples we collect in order to answer many questions about our health and why we get sick.

### **Your privacy is always our first priority.**

Before anyone can look at any information, physical measurements or samples that you provide, they must tell us exactly what information they would like to access, what they will do with that information and what questions they are hoping to answer. Our expert reviewers will consider these requests and only those that meet the highest scientific and ethical standards will be approved.

Even after being approved to receive information from the *Ontario Health Study*, researchers will not be given your name or address. This information will never be released unless you give us permission. None of the information released to researchers will let them identify or contact you.

Once again, thank you for being “part of something big!” I look forward to updating you as we make progress on this important study.

Sincerely,



**John McLaughlin, PhD**

Scientific Lead, Ontario Health Study



**Ontario Health Study**  
**Étude sur la santé en Ontario**

## Principal Investigator

John McLaughlin, PhD, Scientific Lead, Ontario Health Study; Vice-President, Population Studies & Surveillance, Cancer Care Ontario; Professor, Dalla Lana School of Public Health, University of Toronto.

## Funding Resources

The **Ontario Institute for Cancer Research** is funded by the Ontario Ministry of Research and Innovation to conduct research on cancer. **Cancer Care Ontario** is funded by the Ontario Ministry of Health and Long-Term Care to improve cancer services. The **Canadian Partnership Against Cancer** is funded by Health Canada to coordinate national efforts to reduce the number of cases of cancer.

In addition, the **Ontario division of the Canadian Cancer Society** and the **Ontario Agency for Health Protection and Promotion** have recognized the importance of this Study and are endorsing its objectives.

## Purpose of the Research

The *Ontario Health Study* is a large, long-term study that will help researchers learn more about how genes, lifestyle choices and environmental risks can cause chronic diseases. Information gathered from participants will form a confidential health information “bank” that medical researchers will use for approved studies.

Thank you for taking the time to read the information brochure and for asking any questions you may have about the project.

## YOUR CONSENT

By signing this *Consent Form*, I agree to participate in the *Ontario Health Study* and I declare that:

- I have read and understood the information provided to me. I have had the opportunity to ask questions and received satisfactory answers. I was given sufficient time to think it over and make an informed decision regarding my participation.
- I agree to: i) answer detailed questionnaires regarding my health, lifestyle and diet; ii) meet with a nurse; and iii) let the trained staff at an *Ontario Health Study* assessment centre take routine physical measures including standing and sitting heights, weight, body fat percentage, waist and hip circumferences, blood pressure, ankle-brachial index, resting heart rate, bone fragility, lung function and hand grip strength. I understand that I can choose not to respond to a particular question or have certain physical measurements recorded if they make me uncomfortable.
- I agree to provide a blood sample (42 mL or about three tablespoons) and a urine sample. I recognize that I may experience temporary discomfort when the blood sample is taken. I understand there is a small risk of bruising, infection or swelling at the site where the needle is inserted, and that I may feel dizzy or faint. I understand that my blood and urine samples will be stored for future analyses. I recognize that it will be possible for scientists to examine my DNA for research purposes. I accept that the results of those future analyses will not be communicated to me.
- I agree to provide my Health Card number. I accept that information about me contained in administrative databases can be requested by, and sent to, the *Ontario Health Study*. This will continue even if I withdraw from the *Study*, if I can no longer make decisions for myself, or after my death.
- I understand that I can participate in the *Study* even if I choose not to provide my Health Card number, but that the *Study* will be most effective and beneficial to future generations if I do provide my Health Card number.
- I agree to collect environmental samples in my household, such as my drinking water and household dust. These samples may be analysed for environmental contaminants and/or stored for future analyses. I accept that the results of the environmental analyses will not be communicated to me.
- I understand that the results of the physical measures may be the only individual results I receive at the assessment centre. I recognize that these results are not intended to be diagnostic or replace a visit to my doctor or health care professional.
- I accept that information about me contained in my personal medical records may be examined as part of the *Ontario Health Study*. I understand that at all times my personal health information will be protected and my confidentiality maintained.
- I accept that my data and samples, once any information that might directly identify me has been removed, may be used by researchers from Ontario, within Canada (for example, as part of the larger study being carried out across Canada), and other countries for health-related and biomedical research projects that have received the necessary approvals.

- I agree to be contacted again in the future by the *Ontario Health Study* to provide additional information or samples related to its research work. I further agree to be contacted by study staff about whether I want to participate in additional studies conducted in association with the *Study*. I recognize that I can refuse to participate at that time.
- I accept that I will receive no personal financial benefit from the sale of any test or product that may be developed as a result of the data and samples collected by the *Ontario Health Study*.
- I understand that my participation is completely voluntary and that I can withdraw from the project at any time, without giving a specific reason, by calling the number below. I further understand that any information or samples I provide will continue to be available to researchers even if I withdraw from the Study, if I can no longer make decisions for myself, or after my death.
- I accept that the information and samples collected by the *Ontario Health Study* will be kept until at least 2059. At this time, an ethics review process will determine whether the information and samples should be destroyed, made irreversibly anonymous, or kept for further research.

## Contact Personnel

For further information, you may contact the *Ontario Health Study* by:

- Calling 1-866-606-0686
- Writing to Ontario Health Study, Head Office, 620 University Avenue, Toronto ON M5G 2L7
- Visiting [www.ontariohealthstudy.ca](http://www.ontariohealthstudy.ca) or sending an email to: [join@ontariohealthstudy.ca](mailto:join@ontariohealthstudy.ca)

You may contact the **Ontario Health Study Privacy Lead** if you have any questions or concerns about your privacy rights: [privacy@ontariohealthstudy.ca](mailto:privacy@ontariohealthstudy.ca).

You may also contact the **Ethics Review Office at the University of Toronto** if you have any questions or concerns about your rights as a research participant: [ethics.review@utoronto.ca](mailto:ethics.review@utoronto.ca) or 416-946-3273.

## Participant

\_\_\_\_\_  
*Last name*

\_\_\_\_\_  
*First name*

\_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Signature*

ID:

Version 3 - January 28, 2009