

# Melanoma Research Database

## Information for patients and families

Read this information to learn:

- what the melanoma research database is
- why it collects your health information
- how it works
- how we protect your information and right to privacy



As a person who has experienced melanoma, we are asking for your help to create a national Melanoma Research Database.

The database will record information about melanoma and its treatment from patients across Canada. This will help researchers:

- ✓ better understand this complex disease
- ✓ improve treatments and outcomes for future patients

This pamphlet tells you about this research project. You can decide whether or not you wish to take part. If you have any questions or need more information, please call us at 416 946 4501.

**Dr. Marcus Butler, Investigator**                      extension 5485

**Database Project Coordinator**                      416 634 7113

## **What is the purpose of this project?**

This project seeks to develop:

1. A national network of cancer centres that treat melanoma
2. A national database of patient information about melanoma and its treatment

This project builds on a database that was developed in 2010 to collect information about patients treated for melanoma in London, Ontario. A larger database with information from patients across Canada will be more helpful to researchers studying melanoma and its treatment.

The Melanoma Research Database will be a unique resource in the world. It may help answer many future research questions.

## **How will the database be used?**

The database will be used in research to:

- help doctors and researchers learn more about melanoma
- assess the quality and amount of care used to treat melanoma at Princess Margaret Cancer Centre and other cancer centres in Canada
- study ways to improve treatment and prevent the disease

## **How will you collect my information?**

Researchers assigned to this project will copy information from your medical record. This includes information about your medical history, test results and treatments. Only the information in your existing records is needed. No further contact or extra visits to the hospital are required.

The information from all patients in all participating cancer centres will be stored in one secure, online database.

## **How will you protect the privacy of my personal health information?**

At University Health Network (UHN) we treat patients' health information with respect and sensitivity. We follow UHN's policies, Ontario's Personal Health Information Protection Act, and all related laws.

To protect the privacy and the confidentiality of your health information:

- We will assign a code number to your private information. This code is used instead of your name or medical record number.
- The database is protected with a password. Access is restricted to people who are approved by the UHN's Research Ethics Board.
- Access to your personal health information will take place under the supervision of the Principal Investigator.

- We will keep all patient information in a highly secure data centre.
- We will not use your name or any identifying information in any publication or presentations.

We will not give your name or any identifying information to anyone who is not involved in this project.

If you have questions regarding the privacy, please contact UHN's privacy Office at:

Phone: 416 340 4800 extension 6937

Email: [privacy@uhn.ca](mailto:privacy@uhn.ca)

## **What are the risks and benefits of taking part?**

### **Risks**

- There are no physical risks of allowing your information to be stored in the database.
- Whether you decide to take part in the database or not, your choice will not affect your care in any way.
- We will do our very best to keep your personal information private and confidential. However, it is not possible to guarantee absolute confidentiality.

### **Benefits**

- You may or may not directly benefit from taking part. We hope that the information can be used in the future to benefit people with melanoma.

## **What if I don't want my information in the database?**

You do not have to take part in this project. The decision to do so is your choice. Your choice will not affect your care in any way.

If you do not want your personal health information to be collected and used for research, please tell your doctor. You do not have to explain your decision. Your doctor will tell the Database Project Coordinator and your information will not be collected for the database.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416 581 7849.

The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

The development of patient education resources is supported by the Princess Margaret Cancer Foundation.

Visit [www.uhnpatienteducation.ca](http://www.uhnpatienteducation.ca) for more health information.

Contact us to provide feedback or request this brochure in a different format, such as large print or electronic formats: [pfep@uhn.ca](mailto:pfep@uhn.ca)

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