



LEUKEMIA/BONE MARROW TRANSPLANT PROGRAM OF BRITISH COLUMBIA  
Division of Hematology

**Study Information and Consent Form**

***Biobank:***

***HEMATOLOGY CELL BANK OF BRITISH COLUMBIA***

***A collection of tissue and data***

**COLLECTION AND TISSUE BANKING OF BLOOD, BONE MARROW MATERIAL, PERIPHERAL BLOOD STEM CELLS OR LEUKAPHERESIS PRODUCT AND COLLECTION OF CLINICAL DATA FROM PERSONS WITH HEMATOLOGIC MALIGNANCIES OR OTHER HEMATOLOGIC DISORDERS (AND FROM PERSONS WITH NORMAL BLOOD, BONE MARROW MATERIAL, AND/OR PERIPHERAL BLOOD STEM CELLS) FOR RESEARCH ON THE DEVELOPMENT AND TREATMENT OF BLOOD DISEASES**

**Biobank Custodian: Dr. David Sanford**

UBC Department of Medicine

British Columbia Cancer

604-875-4863

**PLEASE NOTE:**

**GIVE A COMPLETE PHOTOCOPY OF THE CONSENT TO THE DONOR AND CHECK THE BOX ABOVE. ONLY RETURN ORIGINAL CONSENT SIGNATURE PAGE TO THE HEMATOLOGY CELL BANK COORDINATOR**

Division of Hematology  
2775 Laurel Street, 10<sup>th</sup> Floor  
Vancouver, BC V5Z 1M9  
Phone: 604.875.4863  
Fax: 604.875.4763  
[www.leukemiabmtprogram.com](http://www.leukemiabmtprogram.com)

Supported by:  
BC Cancer  
Vancouver Coastal Health  
University of British Columbia

*Interim Director:*

Sujaatha Narayanan  
MBBS, MRCP, FRCPath

*Members:*

Yasser R. Abou Mourad  
MD, FRCPC, FACP

Michael J. Barnett  
BM, FRCPC, FRCP, FRCPath

Raewyn C. Broady  
MBChB, FRACP, FRCPC

Donna L. Forrest  
MD, FRCPC

Alina S. Gerrie  
MD, MPH, FRCPC

Kevin A. Hay  
MD, MSc, FRCPC

Donna E. Hogge  
MD, PhD, FRCPC

Florian C. Kuchenbauer  
MD, PhD

Stephen H. Nantel  
MD, FRCPC

Thomas J. Nevill  
MD, FRCPC

Maryse M. Power  
MB, MRCPI, FRCPath

David S. Sanford  
MD, FRCPC

Kevin W. Song  
MD, FRCPC

Heather J. Sutherland  
MD, PhD, FRCPC

Cynthia L. Toze  
MD, MHSc, FRCPC

Jennifer K. White  
MD, MSc, FRCPC

## **PURPOSE**

A biobank collects, stores and gives out human samples (tissue, blood, fluids, stem cells, etc) and related health information, to researchers, for the purpose of future research. You are being invited to donate your samples and/or information to the biobank. Researchers who are looking for new ways to detect, treat and maybe even prevent cancer, will access the samples and information that are stored at the Hematology Cell Bank of British Columbia (HCB) to conduct their own studies. Because cancer research is always progressing, it is unknown at this time what future research will be done on your samples or information, but some of these studies may lead to new products, such as drugs or tests for cancer, or may look at genes (which carry information needed to build and operate a human body) and how genes affect health or response to treatment. Some of collected samples may be transferred to mouse or animal models to simulate cancer biology and learn more about normal blood development, disease detection, treatment and/or prevention.

## **PARTICIPATION**

You may participate in this biobank if you are 18 years of age or older, and you are a healthy person

Your participation is entirely voluntary. Please take as much time as you need to decide.

## **WHAT IS INVOLVED?**

If you decide to participate in this biobank, research samples will be collected for the duration of time you have decided to donate your tissue. This may involve sample collected when you are first donating samples or at a later follow-up appointment.

### **Tissue**

No special test or procedure is required to donate your tissue – peripheral blood stem cells or harvested stem cells. At the time when you are already undergoing a bone marrow harvest or peripheral blood stem cell collection, the hematologist or hematopathologist will remove whatever tissue is required for your hematopoietic stem cell transplant donation. Whenever possible, the biobank samples will be collected as an extra: harvested stem cells (2-5 teaspoons) or peripheral stem cells (1-2 teaspoons).

There may be times when you undergo a clinical investigation (for example there may be tests done relevant to healthcare for the recipient) and blood or bone marrow material is collected. Some of this tissue will be used for diagnostic purposes and stored by the Department of Pathology. The remainder is usually discarded, but the Hematology Cell Bank would like to collect and store this remaining material for researchers to use in ongoing and future projects.

### **Blood**

Blood samples may be collected in a single collection prior to the collection of your peripheral blood stem cell or bone marrow harvest. Whenever possible, the biobank samples will be collected as an extra blood sample (about 3-4 teaspoons) at the same time as blood samples are being obtained from a vein in your arm for your donation/ clinical purposes. If we are unable to obtain an extra sample when your donation samples are being obtained then we may ask you to provide a blood sample just for this

biobank. This blood sample would be collected **only once** and is optional. You may still donate to the biobank even if you do not want to provide a blood sample outside of a donation sample collection.

### **Information**

We will ask you for some basic information. This will include things like name, age, sex, and race or ethnic group. We will collect information from your medical records including those records at VGH or BC Cancer. Information may include results of tests, medical procedures, images (such as X-rays), and/or medicines you take if any.

### **DURATION OF STORAGE**

The samples will be stored securely and indefinitely until they have been entirely used up. It is important to do this because the research that can be conducted using your blood and/or stem cells and related clinical data continuously improves.

### **BENEFITS**

You should not expect to get direct health benefits from donating to this biobank. The main reason you may want to take part is to help researchers find new ways to prevent, detect, and treat cancer.

### **RISKS**

#### **Physical Risks**

There are no physical risks to you when the Hematology Cell Bank of BC collects tissue left over and/or extra samples from donation and/or procedure you are undergoing except what is with procedure itself. In most instances, the Hematology Cell Bank of BC obtains blood samples only when a clinical sample is obtained. But when blood is drawn, you may feel brief pain or have some bruising from the needle. Infection, light-headedness, and fainting are also possible, but unlikely.

### **CAN YOU STOP TAKING PART IN THE BIOBANK?**

Participation in this biobank is entirely voluntary. You can withdraw your sample(s) at any time for any reason without any consequences to your medical care. If you want to withdraw your samples, call the Biobank at 604-875-4111 extension 69517, the Hematology Cell Bank Coordinator to let us know. We will arrange to meet with you or we will send you a form with several options so you can tell us what to do with your unused sample(s).

Please note that we cannot get back samples or information that we have already given out to researchers.

### **PRIVACY & CONFIDENTIALITY**

Federal and provincial privacy laws give safeguards for privacy, security, and authorized access to information. We will not give information that identifies you to anyone without your permission, except as required by law.

However, there is a risk that someone could get access to the information we have stored about you, it could be revealed inappropriately or accidentally, and the risk of someone identifying you may increase in the future as people find new ways of tracing

information. Depending on the nature of the information, such a release could upset or embarrass you, or be misused. For example, it could be used to make it harder for you to get or keep a job or insurance. There are laws against this kind of misuse in Canada, but they may not give full protection, and laws in other countries may not be as strict as those in Canada, so when your information and samples are sent to places outside of Canada, you may not be afforded the same rights. We believe the chance these things will happen is very small, but we cannot make guarantees. Your privacy and the confidentiality of your data are very important to us, and we will make every effort to protect these as described below.

**Study-related data and coding:**

- All information gathered for use in the biobank is referred to as the ‘study-related data’. This data may include your medical records, biological materials, genetic information, etc. The study-related data will be transformed into datasets that can be analyzed. You will be assigned a unique code that will be used to track your study-related data. This unique code does not include any personal information that could identify you, and will be used on all study-related data that leave BC Cancer or VGH unless otherwise specified in this form (this is referred to as ‘coded data’).
- Coded data (including genetic information) resulting from analyses being done on samples from this biobank may be pooled and shared with researchers from around the world for future studies that are unknown at this time. It may also be added to public databases, published, or presented at scientific meetings. The aim of these future studies is to benefit people by improving our understanding of health conditions like cancer.

**WHO WILL HAVE ACCESS TO YOUR SAMPLES AND STUDY-RELATED DATA?**

Researchers can ask to study the materials stored in the biobank. This includes researchers from BC Cancer, as well as from other universities, the government, and drug- or health-related companies. Some researchers will be from Canada, and some may be from other countries around the world. All researchers applying will be required to submit details of their project and a science committee at the biobank will review each request. There may also be an ethics review. This kind of review is to make sure that your welfare and rights are protected. HCB samples will only be released to Research Ethics Board approved projects. Research records and medical records identifying you may also be inspected in the presence of the Investigator or his or her designate by representatives of Health Canada and the BC Cancer Research Ethics Boards for the purpose of monitoring the research.

The HCB samples and information learned from analyzing them may be shared with other researchers around the world conducting research. This may include analysis of the genetic code in your cells. Any such genetic code analysis will only be shared with other researchers who have pledged to keep the information confidential, using secure methods of information exchange that preserve confidentiality. The shared information itself will **not** include any traditionally used information that identifies you such as your name, address, telephone number or social security number. Access to this protected

information will be allowed for projects using the information for research relevant to the normal hematology biology and cancer.

### **COSTS, REIMBURSEMENT and COMPENSATION**

There are no costs to you for taking part in the Biobank. You will not be paid for taking part in this study. The research may lead to new tests, drugs, or other products for sale. If it does, you will not get any payment.

Your biological samples and information collected for this biobank will not be used for commercial re-sale. Researchers or companies who receive material and/or data must agree that material and/or data will not be sold or used for commercial purposes and will only be used to support cancer research. Researchers may be charged a fee to help cover some of the costs of storage, release, and overall operation of the Hematology Cell Bank of BC.

### **WHO CAN YOU CONTACT IF YOU HAVE QUESTIONS?**

If you have any questions or desire further information with respect to this study before or during participation, you may contact the Nerkeza Andjelic Project Coordinator at 604-875-4111 extension 69517

You can contact the BC Cancer Research Ethics Board (REB) about your rights as a research participant at [reb@bccancer.bc.ca](mailto:reb@bccancer.bc.ca), or 604.877.6284. Please provide the reference number H19-01373 when contacting the REB so the staff can better assist you.

Signing this consent form in no way limits your legal rights against the investigators, or anyone else involved in this biobank.

You will be given a copy of this signed and dated consent form prior to participating in this biobank, and a copy will also be included in your biobank records.

**Primary Research Investigators:** Vancouver General Hospital, UBC Department of Medicine, BC Genome Sciences Centre, BC Cancer, St. Paul's Hospital, Women's and Children's Hospital and additional BC Hospital centres:

Dr. Yasser Abou Mourad  
Dr. Raewyn Broady  
Dr. Helen Bruyere  
Dr. Mike Delorme  
Dr. Connie Eaves  
Dr. Donna Forrest  
Dr. Lynda Foltz  
Dr. Alina Gerrie  
Dr. Lawrence Haley  
Dr. Jason Hart  
Dr. Kevin Hay  
Dr. Robert Holt  
Dr. Xiaoyan Jiang  
Dr. Aly Karsan  
Dr. Gerald Krystal  
Dr. Florian Kuchenbauer  
Dr. Wendy Lam  
Dr. Peter Lansdorp  
Dr. Heather Leitch

Dr. James Lim  
Dr. Stephen Nantel  
Dr. Sujaatha Narayanan  
Dr. Thomas Nevill  
Dr. Willie Pewarchuk  
Dr. Maryse Power  
Dr. Khaled Ramadan  
Dr. Gregory Reid  
Dr. David Sanford  
Dr. Kirk Schultz  
Dr. Kevin Song  
Dr. Peter Stirling  
Dr. Heather Sutherland  
Dr. Fumio Takei  
Dr. Cynthia Toze  
Dr. Ly Vu  
Dr. Andrew Weng  
Dr. Angela Brooks-Wilson  
Dr. Jennifer White  
Dr. Adrian Yee



Yes  No [Note: For typical situations where the person conducting the consent discussion simply reads the consent with the participant to ensure that informed consent is properly obtained, check “no”.]

If yes, please check the relevant box and complete the signature space below:

The consent form was read to the participant, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant (please check if participant is unable to read).

The person signing below acted as an interpreter for the participant, during the consent process (please check if an interpreter assisted during the consent process).

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Signature of Person Assisting  
in the Consent Discussion

Printed name

Date