

# British Columbia Cancer Agency Centre for Lymphoid Cancer *Newsletter* *Lymphoma ♦ Leukemia ♦ Myeloma*

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*dedicated to curing the lymphoid cancers*

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- How can you participate in lymphoid cancer research?
- What actually happens when you participate in lymphoid cancer research?

### **Lymphoid Cancer Research: What can you do?**

We here at the BC Cancer Agency Centre for Lymphoid Cancer thought you would like to learn how you can help with research leading to increasing cures of lymphoid cancer (non-Hodgkin lymphoma, Hodgkin lymphoma, myeloma and lymphocytic leukemia). The research we carry out is entirely dependent on the tissue and blood specimens donated by our patients with their consent to use them for research purposes. This is where you come in. It is our goal to include every lymphoid cancer patient in British Columbia in this research.

Many of you have already spoken with us about research and signed a consent form allowing us to include you in our research - thank you! If you're not sure if you have done this or have any questions you can contact our research coordinator at 604-675-8000 x 7632 or by email to [clc@bccancer.bc.ca](mailto:clc@bccancer.bc.ca). You can also download and review the consent form [here](#).

Even if you have already agreed to participate you can still help our efforts by promoting research to those around you. Getting the word out is one of the biggest challenges to including all interested patients and families in this type of research. We would also welcome any suggestions you may have about how we can more effectively reach out to people to participate to our research efforts.

### **Lymphoid Research: What actually happens?**

The process leading to lymphoid cancer research starts when a lymphoid cancer is first

diagnosed, usually when a biopsy of involved tissue is obtained or sometimes, as often happens with chronic lymphocytic leukemia, when a blood specimen reveals the presence of lymphoid cancer cells. Once a diagnosis has been made, the patient is referred to an oncologist or hematologist for assessment and treatment planning. That is all part of standard care and precedes any participation in research. Research starts when the patient with lymphoid cancer agrees to participate by providing written permission for the research to proceed.

Researchers in the BCCA Centre for Lymphoid Cancer have developed a consent form that explains what type of research we conduct, how the patient can participate and what benefits may result. You can download the consent form [here](#). Fortunately, patients can participate in this research with a minimum of effort and very little risk or inconvenience. The written consent gives permission to the CLC researchers to have access to three key resources:

- The research participant's medical records
- Leftover tissue from the biopsy that demonstrated the presence of the lymphoid cancer
- One small blood sample from which normal DNA (the genetic code that instructs cells how to behave) can be extracted: usually just 2-3 teaspoons of blood

### **Lymphoid Research: Why does the CLC need those resources?**

The CLC researchers need **access to each research participant's medical record** so that we can better understand what factors may have led to the development of the lymphoid cancer and what becomes of participants after they are treated for their lymphoid cancer. A person's medical record is very private information so the researchers follow very careful procedures to protect research participant's privacy and

confidentiality. Fortunately, with over 30 years of experience conducting research involving more than 30,000 patients and research participants, the BCCA Centre for Lymphoid Cancer has never had even a single instance of loss of privacy or confidentiality.

**Access to leftover tissue from the research participant's diagnostic biopsies** is crucial to the CLC's research. Malignant lymphoid cancer cells are different from normal cells. Indeed, those key differences are what make the cancer cells malignant. These cancer cells proliferate (grow) when they should not, metastasize (spread) to parts of the body where they should not go and push aside or even destroy normal cells as they accumulate in the body. They do this because mistakes have been coded into their genetic instructions or pieces of the genetic instructions that make cells behave normally have been lost. Identifying these genetic mistakes or determining which crucial instructions have gone missing is fundamentally important in cancer research. The search for these mistakes or missing genetic instructions is at the core of the CLC's research program.

The only way to determine what is different about lymphoid cancer cells is to compare them to normal cells. That is why the CLC's researchers need **a source of normal cells, usually from a small blood specimen**. There are trillions (1 trillion = 1,000,000,000,000 !!) of cells in your body and every one of them has thousands of genetic instructions controlling many hundreds of processes and functions every minute of every day. Researchers can only isolate the unique errors and mistakes in lymphoid cancer cells by comparing them to normal cells. Fortunately, there are millions of the necessary normal cells in just a few teaspoons of blood.

### **Where does the lymphoid cancer research take place?**

The lymphoid cancer research conducted by the BCCA Centre for Lymphoid Cancer takes place all across the province of British Columbia and includes research participants from every city, town and locale across the province. That is one of the aspects of cancer research that is unique in British Columbia, often referred to as

population based research. Even as the CLC's research reaches across the province, however, some of the actual laboratory processes take place in special facilities in Vancouver and Victoria where specialized laboratory procedures can be employed using state of the art techniques. This allows CLC researchers to include everyone in BC in this world-class research. The technology and expertise accessible to our group allow us to stay at the cutting edge of lymphoid cancer research and to push the boundaries of knowledge in this area.

### **Lymphoid Cancer Research: What can you do?**

Here are some concrete steps you can take to support and encourage lymphoid cancer research in British Columbia:

- Share this newsletter with anyone you think might want to help with the CLC's research
- If you have or had a lymphoid cancer and have not done so already, download our [BCCA CLC Lymphoid Consent Form](#), review it carefully and, if you would like to participate in this research, complete and sign the form, make a copy for yourself and then submit the original to our research coordinator by mail to **CLC Research Coordinator, c/o Arla Yost, BC Cancer Research Centre, 675 West 10<sup>th</sup> Avenue, Vancouver, BC V5Z 4E6**.
- The CLC Research Coordinator will send you a laboratory blood test requisition that you can take to any hospital lab or Life Lab in BC to submit the necessary normal blood sample

On behalf of all of the researchers conducting lymphoid cancer research at the BCCA Centre for Lymphoid Cancer: THANK YOU !

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