



200 First Street SW
Rochester, Minnesota 55905
507-284-2511

June 21, 2019

«First_Name» «Last_Name»
«Current_address_line1» «Current_address_line2»
«City», «State» «Zip_code»

Dear «First_Name» «Last_Name»:

Thank you for taking the time to discuss your health with us as part of our ongoing research study.

At your convenience, please complete the following document(s):

(documents included in letter are indicated below)

LEO 12 month Follow Up Questionnaire

When you complete the Questionnaire(s), please send them back in the enclosed postage paid envelope(s).

All information will be kept strictly confidential and will not become part of your medical record. If at any time you have any questions concerning this research study, please do not hesitate to contact us at 1-800-610-7093.

Thank you. Your participation is greatly appreciated.

Sincerely,

The Lymphoma Research Team



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Lymphoma Epidemiology of Outcomes (LEO) Follow-up Questionnaire (12/24/36 months)

****please answer based on what has occurred since the last follow-up (date)****

Date Form Completed	____/____/____ (mm/dd/yyyy)
What is your current weight?	_____ pounds
Have you received new treatment for lymphoma?	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (Please answer below) Clinic/Hospital Name where treatment was received:
Have you had a relapse or progression?	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (Please answer below) Clinic/Hospital Name where relapse/progression was detected:
Have you had any CT or PET scans to assess your lymphoma status?	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (Please answer below) Clinic/Hospital Name where scan was done:
Have you been diagnosed with another type of cancer?	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (Please answer below) Clinic/Hospital Name where new cancer was diagnosed:
Heart Disease	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (select all that apply) <ul style="list-style-type: none"> <input type="checkbox"/> Coronary Heart Disease or Heart Attack (include stents) <input type="checkbox"/> Congestive Heart Failure <input type="checkbox"/> Pericardial Disease or Cardiomyopathy <input type="checkbox"/> Heart Valve Disease <input type="checkbox"/> Heart Rhythm Problems (Arrhythmias or Atrial Fibrillation) <input type="checkbox"/> Other Heart Disease
Stroke	<input type="checkbox"/> No <input type="checkbox"/> Yes
Sugar Diabetes	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (select type below) <ul style="list-style-type: none"> <input type="checkbox"/> Type 1 <input type="checkbox"/> Type 2 <input type="checkbox"/> Type Unknown

Lymphoma Epidemiology of Outcomes (LEO) Follow-up Questionnaire (12/24/36 months)

****please answer based on what has occurred since the last follow-up (date)****

Respiratory (breathing) disease	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (select all that apply) <input type="checkbox"/> Asthma <input type="checkbox"/> Emphysema <input type="checkbox"/> Chronic bronchitis <input type="checkbox"/> Chronic obstructive pulmonary disease
Hepatitis	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (select all that apply) <input type="checkbox"/> Hepatitis A <input type="checkbox"/> Hepatitis B <input type="checkbox"/> Hepatitis C <input type="checkbox"/> Don't know
Other Liver problems	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (select all that apply) <input type="checkbox"/> Cirrhosis <input type="checkbox"/> Non-alcoholic liver disease
Digestive problems	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (select all that apply) <input type="checkbox"/> Ulcer <input type="checkbox"/> Colitis
Sinusitis	<input type="checkbox"/> No <input type="checkbox"/> Yes
Shingles	<input type="checkbox"/> No <input type="checkbox"/> Yes
Progressive Multifocal Leukoencephalopathy ("PML")	<input type="checkbox"/> No <input type="checkbox"/> Yes
Osteoporosis (Brittle Bones)	<input type="checkbox"/> No <input type="checkbox"/> Yes
Hip Fracture (broken hip)	<input type="checkbox"/> No <input type="checkbox"/> Yes
Other Broken Bones	<input type="checkbox"/> No <input type="checkbox"/> Yes
Premature Menopause	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Not applicable
Infertility	<input type="checkbox"/> No <input type="checkbox"/> Yes
Taken medication or seen a health care provider for depression?	<input type="checkbox"/> No <input type="checkbox"/> Yes
Taken medication or seen a health care provider for anxiety?	<input type="checkbox"/> No <input type="checkbox"/> Yes
Taken medication or seen a health care provider for memory problems?	<input type="checkbox"/> No <input type="checkbox"/> Yes

Lymphoma Epidemiology of Outcomes (LEO) Follow-up Questionnaire (12/24/36 months)

****please answer based on what has occurred since the last follow-up (date)****

Blood Clot	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (Please select all that apply) <input type="checkbox"/> Deep Vein Thrombosis (DVT) Clot in (arms?), legs or abdomen <input type="checkbox"/> Pulmonary Embolism (PE) Clot in lungs
Are you currently on Blood Thinning Medication? (other than aspirin or Plavix)	<input type="checkbox"/> No (skip to next question) <input type="checkbox"/> Yes (Please provide type below) <input type="checkbox"/> Coumadin (Warfarin) <input type="checkbox"/> enoxaparin (Lovenox) <input type="checkbox"/> dabigatran (Pradaxa) <input type="checkbox"/> apixaban (Eliquis) <input type="checkbox"/> rivaroxaban (Xarelto) <input type="checkbox"/> Heparin <input type="checkbox"/> other
How many times have you fallen in the last 6 months?	_____ (Number of times, if zero, enter 0)
Have you stayed overnight in the hospital in the last 6 months?	<input type="checkbox"/> No <input type="checkbox"/> Yes (Please answer below) REASON: <input type="checkbox"/> Infection <input type="checkbox"/> Cancer Treatment <input type="checkbox"/> Other: _____

These next questions ask about different ways lymphoma, its treatment, or the lasting effects of that treatment may have affected your work – that is, your hours, duties, or employment status.

As you answer these questions, please think about the entire time from when you were first diagnosed with lymphoma to now.

At any time from when you were first diagnosed with lymphoma until now, were you working for pay at a job or business?	<input type="checkbox"/> No <input type="checkbox"/> Yes
IF YES to above question: At any time since your diagnosis, did you take extended paid time off from work, unpaid time off, or make a change in your hours, duties, or employment status?	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Not applicable
Because of your lymphoma, its treatment, or the lasting effects of that treatment, did any of your caregivers ever take extended paid time off work, unpaid time off, or make a change in their hours, duties or employment status?	<input type="checkbox"/> No <input type="checkbox"/> Yes
Because of your lymphoma, its treatment, or the lasting effects of that treatment, did <u>you</u> or any of your caregivers take an extra job or work additional hours?	<input type="checkbox"/> No <input type="checkbox"/> Yes
Have you or has anyone in your family had to borrow money or go into debt because of your lymphoma, its treatment, or the lasting effects of that treatment?	<input type="checkbox"/> No <input type="checkbox"/> Yes

Lymphoma Epidemiology of Outcomes (LEO) Follow-up Questionnaire (12/24/36 months)

****please answer based on what has occurred since the last follow-up (date)****

Did you or your family ever file for bankruptcy because of your lymphoma, its treatment, or the lasting effects of that treatment?	<input type="checkbox"/> No <input type="checkbox"/> Yes
Please think about medical care visits for lymphoma, its treatment, or the lasting effects of that treatment. Have you ever been unable to cover your share of the cost of those visits?	<input type="checkbox"/> No <input type="checkbox"/> Yes
At any time since you were first diagnosed with lymphoma, did you get all of the medical care, tests, or treatments that you or your doctor believed were necessary? <input type="checkbox"/> No - if no, please answer reason to right (select all that apply) <input type="checkbox"/> Yes, move to next question below	<input type="checkbox"/> couldn't afford care <input type="checkbox"/> insurance company wouldn't approve or pay for care <input type="checkbox"/> had problems getting to the doctor's office <input type="checkbox"/> doctor did not accept your insurance <input type="checkbox"/> couldn't get time off work <input type="checkbox"/> didn't know where to go to get care <input type="checkbox"/> couldn't get child/adult care <input type="checkbox"/> didn't have time – care/test/treatment took too long <input type="checkbox"/> other reason
Have you or your family had to make any other kinds of financial sacrifices because of your lymphoma, its treatment, or the lasting effects of that treatment?	<input type="checkbox"/> No <input type="checkbox"/> Yes
Have you ever worried about having to pay large medical bills related to your lymphoma?	<input type="checkbox"/> No <input type="checkbox"/> Yes
We ask participants about their economic backgrounds because we think it is important to understand how people from different backgrounds differ in their experiences with lymphoma and treatment choices. Using the categories to the right, please indicate the annual income of your household. Include yourself and anyone with whom you live and share finances.	<input type="checkbox"/> Less than \$21,000 <input type="checkbox"/> \$21,000 - \$39,999 <input type="checkbox"/> \$40,000 - 65,999 <input type="checkbox"/> \$66,000 - \$105,999 <input type="checkbox"/> \$106,000 or more <input type="checkbox"/> I don't know <input type="checkbox"/> I choose not to answer

Please circle the number (0-10) best reflecting your response to the following that describes your feelings **during the past week, including today.**

Your Overall Quality of Life

0	1	2	3	4	5	6	7	8	9	10
As BAD as it can be						As GOOD as it can be				

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

∴ PHYSICAL WELL BEING	Not at all	A little bit	Some what	Quite a bit	Very Much
I have a lack of energy	0	1	2	3	4
I have Nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4

«LEO_ID»
 «LOCAL_ID»
 TIMEPOINT: «timepoint»

Lymphoma Epidemiology of Outcomes (LEO) Follow-up Questionnaire (12/24/36 months)

****please answer based on what has occurred since the last follow-up (date)****

I am forced to spend time in bed	0	1	2	3	4
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∴ SOCIAL/FAMILY WELL BEING	Not at all	A little bit	Some what	Quite a bit	Very Much
I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	0	1	2	3	4
I feel close to my partner (or the person who is my main support)	0	1	2	3	4
<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box <input type="checkbox"/> and go to the next section</i>					
I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you **during the past 7 days.**

∴ EMOTIONAL WELL BEING	Not at all	A little bit	Some what	Quite a bit	Very Much
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry about dying	0	1	2	3	4
I worry that my condition will get worse	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you **during the past 7 days.**

∴ FUNCTIONAL WELL BEING	Not at all	A little bit	Some what	Quite a bit	Very Much
I am able to work (include work at home)	0	1	2	3	4
My work (include work at home) is fulfilling	0	1	2	3	4
I am able to enjoy life	0	1	2	3	4
I have accepted my illness	0	1	2	3	4
I am sleeping well	0	1	2	3	4
I am enjoying the things I usually do for fun	0	1	2	3	4
I am content with the quality of my life right now	0	1	2	3	4

Lymphoma Epidemiology of Outcomes (LEO) Follow-up Questionnaire (12/24/36 months)

****please answer based on what has occurred since the last follow-up (date)****

By circling one (1) number per line, please indicate how true each statement has been for you **during the past 7 days.**

***ADDITIONAL CONCERNS	Not at all	A little bit	Some what	Quite a bit	Very Much
I have certain parts of my body where I experience pain	0	1	2	3	4
I am bothered by lumps or swelling in certain parts of my body (eg neck, armpits or groin)	0	1	2	3	4
I am bothered by fevers (especially of high body temperature)	0	1	2	3	4
I have night sweats	0	1	2	3	4
I am bothered by itching	0	1	2	3	4
I have trouble sleeping at night	0	1	2	3	4
I get tired easily	0	1	2	3	4
I am losing weight	0	1	2	3	4
I have a loss of appetite	0	1	2	3	4
I have trouble concentrating	0	1	2	3	4
I worry about getting infections	0	1	2	3	4
I worry that I might get new symptoms of my illness	0	1	2	3	4
I feel isolated from others because of my illness or treatment	0	1	2	3	4
I have emotional ups and downs	0	1	2	3	4
Because of my illness, I have difficulty planning for the future	0	1	2	3	4

*Scored Patient-Generated Subjective Global Assessment (PG-SCA) ©FD Ottery 2005, 2006, 2015 v3.22.15

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∴ FACTG English (Universal) 16 November 2007 Copyright 1987, 1997

Thank you for taking the time to complete this form.

If at any time you have questions, please contact us at: 1-800-610-7093