

PATIENT QUESTIONNAIRE

A1. Which statement describes how you feel most of the time:

- " 1...Normal, no difficulties with daily activities
- " 2...Able to carry on normal activities, minor problems
- " 3...Normal activity with effort
- " 4...Able to care for self, but unable to carry on normal activity or active work
- " 5...Require occasional assistance, but able to care for more of needs
- " 6...Require considerable assistance and frequent medical care
- " 7...Disabled, require special care and assistance
- " 8...Severely disabled, hospitalized
- " 9...Very sick, hospitalized

A2. On a scale of 0 to 100, with zero being death and one-hundred being perfect health, which number would you say best describes your state of health over the past two weeks?

A3. In general, would you say your health is:

- " 1...Excellent
- " 2...Very good
- " 3...Good
- " 4...Fair
- " 5...Poor

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.**

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy.....	0	1	2	3	4
GP2	I have nausea.....	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
GP4	I have pain.....	0	1	2	3	4
GP5	I am bothered by side effects of treatment.....	0	1	2	3	4
GP6	I feel ill.....	0	1	2	3	4
GP7	I am forced to spend time in bed.....	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends.....	0	1	2	3	4
GS2	I get emotional support from my family.....	0	1	2	3	4
GS3	I get support from my friends.....	0	1	2	3	4
GS4	My family has accepted my illness.....	0	1	2	3	4
GS5	I am satisfied with family communication about my illness.....	0	1	2	3	4
GS6	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.</i>						
<i>If you prefer not to answer it, please check this box <input type="checkbox"/> and go to the next section.</i>						
GS7	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.

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GE1	I feel sad.....	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.....	0	1	2	3	4
GE4	I feel nervous.....	0	1	2	3	4
GE5	I worry about dying.....	0	1	2	3	4
GE6	I worry that my condition will get worse.....	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GF1	I am able to work (include work at home)....	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well.....	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun..	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	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.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
BMT1	I am concerned about keeping my job (include work at home).....	0	1	2	3	4
BMT2	I feel distant from other people.....	0	1	2	3	4
BMT3	I worry that the transplant will not work.....	0	1	2	3	4
	The effects of treatment are worse than I had imagined.....					
BMT4	If you have not been treated for your disease, check here []	0	1	2	3	4
C6	I have a good appetite.....	0	1	2	3	4
C7	I like the appearance of my body.....	0	1	2	3	4
BMT5	I am able to get around by myself.....	0	1	2	3	4
BMT6	I get tired easily.....	0	1	2	3	4
BL4	I am interested in sex.....	0	1	2	3	4
	I have confidence in my nurses.....					
BMT8	Check here if not applicable []	0	1	2	3	4

A4. In general, would you say your quality of life is: (Check one)

- " 1...Excellent
- " 2...Very good
- " 3...Good
- " 4...Fair
- " 5...Poor

A5. Do you currently have chronic graft-versus-host disease (cGVHD)?

- " 1...No
- " 2... Yes, it is mild
- " 3... Yes, it is moderate
- " 4... Yes, it is severe

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days. (for 6 months, 1 year, 2 years survey only)

	Not bothered at all	Slightly bothered	Moderately bothered	Quite bothered	Extremely bothered
SKIN:					
a. Abnormal skin color	0	1	2	3	4
b. Rashes	0	1	2	3	4
c. Thickened skin	0	1	2	3	4
d. Sores on skin	0	1	2	3	4
e. Itchy skin	0	1	2	3	4
EYES AND MOUTH:					
f. Dry eyes	0	1	2	3	4
g. Need to use eyedrops frequently	0	1	2	3	4
h. Difficulty seeing clearly	0	1	2	3	4
i. Need to avoid certain foods due to mouth pain	0	1	2	3	4
j. Ulcers in mouth	0	1	2	3	4
k. Receiving nutrition from an intravenous line or feeding tube	0	1	2	3	4
BREATHING:					
l. Frequent cough	0	1	2	3	4
m. Colored sputum	0	1	2	3	4
n. Shortness of breath with exercise	0	1	2	3	4
o. Shortness of breath at rest	0	1	2	3	4
p. Need to use oxygen	0	1	2	3	4
EATING AND DIGESTION:					
q. Difficulty swallowing solid foods	0	1	2	3	4
r. Difficulty swallowing liquids	0	1	2	3	4
s. Loss of appetite	0	1	2	3	4
t. Vomiting	0	1	2	3	4
MUSCLES AND JOINTS:					
u. Limited joint movement	0	1	2	3	4
v. Weak muscles	0	1	2	3	4
w. Muscle cramps	0	1	2	3	4
x. Weak muscles	0	1	2	3	4
ENERGY:					
y. Loss of energy	0	1	2	3	4
z. Need to sleep more/take naps	0	1	2	3	4
aa. Fevers	0	1	2	3	4
MENTAL AND EMOTIONAL:					
bb. Depression	0	1	2	3	4
cc. Anxiety	0	1	2	3	4
dd. Difficulty sleeping	0	1	2	3	4

OCCUPATIONAL FUNCTIONING ITEMS (FOR BASELINE, 1 YEAR, 2 YEARS ONLY)

The next set of questions has to do with your working at a job or in the home.

O1. Which of the following best describes your current job status?

- | | |
|--|-------------------------------|
| " 1 = Employed outside the home, full-time | " 6 = Temporarily disabled |
| " 2 = Employed outside the home, part-time | " 7 = Permanently disabled |
| " 3 = Homemaker | " 8 = Student |
| " 4 = Retired | " 9 = Other (e.g., volunteer) |
| " 5 = Unemployed, looking for work | |

O2. What kind of work do you do at the present time? (Include work done in the home.)

O3. At the present time, how many hours do you work each week for which you are paid? How many for which you are not paid?

_____ paid hours _____ unpaid hours

O4. Have you attempted to work/go to school but found that you weren't able to?

- " Yes —————> 3a. If YES, what prevents you from working/going to school at the present time?
 " No _____

O5. Is your work/school work as important to you now as it was before your diagnosis? (Explore.)

- " 1 More important
 " 2 About the same importance
 " 3 Less important

O6. Have you changed your goals concerning your work/education as a result of your diagnosis? (Explore.)

- " 1 My goals haven't changed
 " 2 My goals have changed slightly
 " 3 My goals have changed quite a bit
 " 4 My goals have changed completely

These next questions are about how you feel, and how things have been with you mostly within the past two weeks. For each question, please circle a number for the one answer that comes closest to the way you have been feeling.

M1. How happy, satisfied, or pleased have you been with your personal life during the past two weeks?

- " 1...Extremely happy, could not have been more satisfied or please
- " 2...Very happy most of the time
- " 3...Generally satisfied, pleased
- " 4...Sometimes fairly satisfied, sometimes fairly unhappy
- " 5...Generally dissatisfied, unhappy
- " 6...Very dissatisfied, unhappy most of the time

These questions are about how you feel and how things have been with you during the past two weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past two weeks- (Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
M2. Have you felt lonely?	1	2	3	4	5	6
M3. Have you felt that the future looks hopeful and promising?	1	2	3	4	5	6
M4. Has your daily life been full of things that were interesting to you?	1	2	3	4	5	6
M5. Did you feel relaxed and free of tension?	1	2	3	4	5	6
M6. Have you generally enjoyed the things you do?	1	2	3	4	5	6
M7. Have you felt loved and wanted?	1	2	3	4	5	6
M8. Have you been a very nervous person?	1	2	3	4	5	6
M9. Have you felt tense or "high strung"?	1	2	3	4	5	6
M10. Have you felt calm and peaceful?	1	2	3	4	5	6
M11. Have you felt emotionally stable?	1	2	3	4	5	6
M12. Have you felt downhearted and blue?	1	2	3	4	5	6
M13. Were you able to relax without difficulty?	1	2	3	4	5	6
M14. Did you feel that your love relationships, loving and being loved, were full and complete?	1	2	3	4	5	6
M15. Has living been a wonderful adventure for you?	1	2	3	4	5	6

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
M16. Have you felt restless, fidgety, or impatient?	1	2	3	4	5	6
M17. Have you been moody or brooded about things?	1	2	3	4	5	6
M18. Have you felt cheerful, light-hearted?	1	2	3	4	5	6
M19. Were you a happy person?	1	2	3	4	5	6
M20. Have you been in low or very low spirits?	1	2	3	4	5	6

M21. During the past two weeks, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory?

- " 1...No, not at all
- " 2...Maybe a little
- " 3... Yes, but not enough to be concerned or worried about it
- " 4... Yes, and I have been a little concerned
- " 5... Yes, and I am quite concerned
- " 6... Yes, and I am very much concerned about it

M22. Did you feel depressed during the past two weeks?

- " 1... Yes, to the point that I did not care about anything for days at a time
- " 2... Yes, very depressed almost every day
- " 3... Yes, quite depressed several times
- " 4... Yes, a little depressed now and then
- " 5...No, never felt depressed at all

M23. During the past two weeks, have you been in firm control of your behavior, thoughts, emotions, and feelings?

- " 1... Yes, very definitely
- " 2... Yes, for the most part
- " 3... Yes, I guess so
- " 4...No, not too well
- " 5...No, and I am somewhat disturbed
- " 6...No, and I am very disturbed

M24. How much have you been bothered by nervousness, or your "nerves" during the past two weeks?

- " 1...Extremely so tot he point where I could not take care of things
- " 2... Very much bothered
- " 3...Bothered quite a bit by nerves
- " 4...Bothered some, enough to notice
- " 5...Bothered just a little by nerves
- " 6...Not bothered at all by this

M25. During the past two weeks, did you ever think about taking your own life?

- " 1...Yes, very often
- " 2...Yes, fairly often
- " 3...Yes, a couple of times
- " 4...Yes, at one time
- " 5...No, never

M26. During the past two weeks, have you been anxious or worried?

- " 1...Yes, extremely so, to the point of being sick or almost sick
- " 2...Yes, very much so
- " 3...Yes, quite a bit
- " 4...Yes, some, enough to bother me
- " 5...Yes, a little bit
- " 6...No, not at all

M27. How often during the past two weeks, have you been waking up feeling fresh and rested?

- " 1...Always, every day
- " 2...Almost every day
- " 3...Most days
- " 4...Some days, but usually not
- " 5...Hardly ever
- " 6...Never wake up feeling rested

M28. During the past two weeks, have you been under or felt you were under any strain, stress, or pressure?

- " 1...Yes, almost more than I could stand or bear
- " 2...Yes, quite a bit of pressure
- " 3...Yes, some, more than usual
- " 4...Yes, some, but about normal
- " 5...Yes, a little bit
- " 6...No, not at all

These questions are about how you feel and how things have been with you during the past two weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past two weeks- (Circle one number on each line)

	Always	Very Often	Fairly Often	Some times	Almost Never	Never
M29. Did you become nervous or jumpy when faced with excitement of unexpected situations?	1	2	3	4	5	6
M30. When you got up in the morning about how often did you expect to have an interesting day?	1	2	3	4	5	6
M31. Did your hands shake when you tried to do something?	1	2	3	4	5	6
M32. Did you feel that you had nothing to look forward to?	1	2	3	4	5	6
M33. Have you felt like crying?	1	2	3	4	5	6
M34. Have you felt that others would be better off if you were dead?	1	2	3	4	5	6
M35. Did you feel that nothing turned out for you the way you wanted it to?	1	2	3	4	5	6
M36. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
M37. Did you get rattled, upset, or flustered?	1	2	3	4	5	6
M38. Did you find yourself having difficulty trying to calm down?	1	2	3	4	5	6

SECTION D. PLEASE TELL US ABOUT YOURSELF (BASELINE ONLY)

D1. Do you consider yourself to be Latino(a) or Hispanic?

- " 1...No
- " 2...Yes

D2. How would you best describe your race? (Check all that apply):

- " 1...Black
- " 2...American Indian/Alaskan Native
- " 3...Asian
- " 4...Hawaiian/Pacific Islander
- " 5...White
- " 6...Other, please specify _____

D3. What is your gender?

- " 1...Male
- " 2...Female

D4. How old are you?... _____ years

D5. What is your marital status?

- " 1...Married/Living with partner
- " 2...Single, Never married
- " 3...Divorced, Separated
- " 4...Widowed
- " 5...Other, specify _____

D6. What is the highest grade of school you have completed?

- " 1...Grade school
- " 2...Some high school
- " 3...High school graduate
- " 4...Some college
- " 5...College graduate
- " 6...Postgraduate degree

D7. What was your approximate annual family income last year?

- " 1...Under \$15,000
- " 2...\$15,000 - \$24,999
- " 3...\$25,000 - \$49,999
- " 4...\$50,000 - \$74,999
- " 5...\$75,000 - \$99,999
- " 6...\$100,000 or above

D8. Finally, how comfortable were you with most of the questions on this survey?

- " 1...Very comfortable
- " 2...Comfortable
- " 3...A little uncomfortable
- " 4...Very uncomfortable
- " 5...Something else, please tell us in space below

D9. How much stress did completing this survey cause you?

- " 1...None
- " 2...A little
- " 3...Some
- " 4...A lot
- " 5...A great deal

D10. Since many people move and we lose contact with you over time, please provide the name, address and phone number of two people who would be willing to let us contact them to find out your current address. (for example, a parent, child or good friend who lives separately from you). Please be sure that they give permission for us to contact them if you move.

Name: _____

Address: _____

Phone: () _____

Name: _____

Address: _____

Phone: () _____

D11. You will be asked to complete a QOL survey again after you transplant at 100 days post-transplant, 6 months, 1 year and 2 years. Although it is not officially part of the study, may we contact you again at 5 years after your transplant to see how you are doing? We would ask you to complete another QOL survey similar to the one you have just finished.

" 1...Yes

" 2...No