

OFFICE USE ONLY:

Study ID: _____

Date Received: ____/____/____

Site ID: ____ (DFCI=01, MSKCC=02, MDA=03, GSI=04, LRG=05)

Family Name: _____

Project FLAG

Family History Questionnaire

Please print the following information.

Name _____ Today's Date _____

Street Address _____

City _____ State _____ Zip Code _____

Telephone (☐Home ☐Work ☐Cell) () _____ - _____ Ext. _____

Email Address _____

The purpose of this questionnaire is to gather information about GISTs and certain other associated physical conditions in you and your family members.

All of your responses will be kept confidential.

You may skip any questions that you prefer not to answer.

Thank you for completing this questionnaire!

Choose only one response for each question, unless otherwise indicated.

Marking Instructions:

- Make solid marks that fill the circle completely
- Fully erase any marks that you want to change
- Make no stray marks

Correct: ●

Incorrect: ○

Patient Background

1. What is your date of birth?

____/____/____
(Month) (Day) (Year)

2. What is your gender?

- ① Male
- ② Female

3. Please only include blood relatives, both living and deceased.

How many sisters do you have? ____

How many brothers? ____

How many daughters? ____

How many sons? ____

4. Select what best describes your racial background: (Select only one response)

- ① American Indian or Alaskan Native
- ② Asian
- ③ Black or African American
- ④ Native Hawaiian or Other Pacific Islander
- ⑤ White
- ⑥ Other or More Than One Race (specify _____)

5. Are you of Hispanic/Latino origin?

- ① No
- ② Yes

6. What is your highest level of education?

- ① Less than high school (7-9 years)
- ② Some high school (10-11 years)
- ③ High school graduate (including GED)
- ④ Some college or technical school
- ⑤ College graduate
- ⑥ Post-graduate or professional

Diagnosis and Symptoms of GIST

Questions 7 and 8 ask when your GIST was FIRST diagnosed, where it was located and what symptoms led to the diagnosis of GIST. If you never had GIST, skip to Question 10.

7. How old were you when your FIRST GIST was diagnosed? ____

7a. What was the approximate date of your FIRST GIST diagnosis (EX: 01 / 2004)?

____/_____
(month) (year)

8. In what organ was the GIST first located (that is, where did the tumor first start)?

- ① Esophagus
- ② Stomach
- ③ Small intestine (duodenum, jejunum or ileum)
- ④ Large intestine (colon or rectum)
- ⑤ Other (specify): _____
- ⑥ Don't know

9. Have you ever been diagnosed with a second separate GIST? (By a second separate GIST we mean a tumor that is independent from the first one, that is, it is NOT a recurrence or a metastasis from the first GIST.)

- ① No...Skip to Question 10
- ② Yes

9a. If yes, what was the approximate date of your SECOND GIST diagnosed?

____/_____
(month) (year)

9b. In what organ was the SECOND GIST located?

- ① Esophagus
- ② Stomach
- ③ Small intestine (duodenum, jejunum or ileum)
- ④ Large intestine (colon or rectum)
- ⑤ Other (specify): _____
- ⑥ Don't know

9c. Please mark in this box if you have had 3 or more separate GISTs. ①

10. Have you ever been diagnosed with a cancer or a benign tumor other than GIST?

- ① No...Skip to Question 12
② Yes

11. What type of tumor or cancer was it, and where in the body was it located?

| Type of tumor/cancer | Location in Body | Age of Diagnosis |
|----------------------|------------------|------------------|
| 1 | | |
| 2 | | |
| 3 | | |

Other Conditions

12. Indicate whether you have had EACH of the medical conditions listed below. Then indicate how old you were when each condition was FIRST diagnosed.

| | Have you had? | | | Age when you first had condition |
|---|---------------|-----|-----------|----------------------------------|
| | No | Yes | | |
| a. Anemia or other Blood diseases: _____ (Specify type) | ① | ② | | _____ |
| b. Difficulty Swallowing | ① | ② | | _____ |
| c. High Blood Pressure (<u>NOT</u> caused by chemotherapy or other medications) | ① | ② | | _____ |
| <i>The following conditions are uncommon. You probably have only heard of them if you or a relative has had one of them. If you are not sure, please fill-in the bubble corresponding to "Uncertain."</i> | | | | |
| | No | Yes | Uncertain | |
| d. Mastocytosis | ① | ② | ③ | _____ |
| e. Neurofibromatosis | ① | ② | ③ | _____ |
| f. Paraganglioma | ① | ② | ③ | _____ |
| g. Pheochromocytoma | ① | ② | ③ | _____ |
| h. List any other skin lesions or other medical conditions of any kind that you may have now or have had in the past (please specify): _____ _____ _____ | | | | _____ _____ _____ |

Skin History

13. How many times have you seen a dermatologist to check for a skin condition?

- ☐ ① None....*Skip to Question 14*
- ☐ ② Once
- ☐ ③ Twice
- ☐ ④ Three or more times

13a. What were the skin condition(s) that you saw a dermatologist for?

14. A mole is an area of pigment (color) on the skin. Moles are usually brown, and may be flat or raised. How many moles have you had that are at least ¼ inch in diameter (larger than a pencil eraser)? (Please include any moles previously removed in your count)

- ☐ ① None.....(*Skip to Q. 16*)
- ☐ ② 1 or 2
- ☐ ③ 3 to 5
- ☐ ④ 6 to 10
- ☐ ⑤ More than 10
- ☐ ⑥ Don't Know

14a. Where are or were these moles located? (Select all that apply)

- ☐ ① Face
- ☐ ① Lips
- ☐ ① Mouth
- ☐ ① Neck
- ☐ ① Arms
- ☐ ① Hands
- ☐ ① Armpit
- ☐ ① Back
- ☐ ① Legs
- ☐ ① Genital area/Buttocks
- ☐ ① Other (specify) _____

15. Which of the following features do any of your moles have? (Select all that apply)

- ☐ ① Irregular shape
- ☐ ① Borders that are ragged, notched, and/or blurred
- ☐ ① Color is uneven--shades of black, brown, tan, white, red, or blue
- ☐ ① Increased in size

For the first 4 items in the following question, please refer to the photographs on Page 7.

16. Have you ever been told you have any of the skin conditions listed below? (Select all that apply.)

- ☐ ① Café au lait spots (Picture A)
- ☐ ① Melanoma or pre-melanoma (Picture B)
- ☐ ① Nevi (moles) (Picture C)
- ☐ ① Urticaria pigmentosa (Picture D)
- ☐ ① Vitiligo (not pictured)

17. Have you ever noticed a skin rash, change of color, or other skin change that you have not mentioned above?

- ☐ ① No
- ☐ ② Yes (specify): _____

18. Have you ever noticed any lumps or other changes that you have not mentioned above?

- ☐ ① No
- ☐ ② Yes (specify): _____

19. Were you born with any birthmarks or birth defects?

- ☐ ① No
- ☐ ② Yes (specify): _____

20. Family History. Please place a check mark (✓) in the boxes below for each family member who was diagnosed with a cancer or unusual non-cancerous condition as indicated. Please provide your best estimate of the age of first diagnosis for cancer(s) in the shaded boxes of the first four columns below. If your estimate falls in a range of years, please provide the midpoint of the range. For example, if your relative was diagnosed in their 40's, write 45. We will be verifying this information later, therefore it is not necessary for your answer to be perfectly accurate.

If none of your family members has had any of these conditions, please check (✓) this box [] then proceed to Q. 22.

| | GIST | Sarcoma | Melanoma | Other Cancer(s) (e.g., colon, stomach, breast, kidney, prostate, brain, thyroid) - Specify which cancer - | Neuro- fibro- matosis (NF1) | Mastocytosis/ Urticaria pigmentosum | Any other unusual skin conditions (e.g., Vitiligo) | Other rare tumor(s) (e.g., Pheochromo- cytoma, Paraganglioma) |
|-------------------------------|---|---------|----------|--|--------------------------------------|---|---|--|
| | In the shaded boxes, please provide the AGE OF FIRST DIAGNOSIS for the cancer(s). | | | | | | | |
| FIRST DEGREE RELATIVES | | | | | | | | |
| Mother | | | | | | | | |
| Father | | | | | | | | |
| Sister 1 | | | | | | | | |
| Sister 2 | | | | | | | | |
| Sister 3 | | | | | | | | |
| Brother 1 | | | | | | | | |
| Brother 2 | | | | | | | | |
| Brother 3 | | | | | | | | |
| Daughter 1 | | | | | | | | |
| Daughter 2 | | | | | | | | |
| Daughter 3 | | | | | | | | |
| Son 1 | | | | | | | | |
| Son 2 | | | | | | | | |
| Son 3 | | | | | | | | |
| | | | | | | | | |

| | GIST | Sarcoma | Melanoma | Other Cancer(s) (e.g., colon, stomach, breast, kidney, prostate, brain, thyroid) - Specify which cancer - | Neuro- fibro- matosis (NF1) | Mastocytosis/ Urticaria pigmentosum | Any other unusual skin conditions (e.g., Vitiligo) | Other rare tumor(s) (e.g., Pheochromo- cytoma, Paraganglioma) |
|---|------|---------|----------|--|--------------------------------------|---|---|--|
| In the shaded boxes, please provide the AGE OF FIRST DIAGNOSIS for the cancer(s). | | | | | | | | |
| RELATIVES – MATERNAL SIDE | | | | | | | | |
| Grandmother | | | | | | | | |
| Grandfather | | | | | | | | |
| Aunt 1 | | | | | | | | |
| Aunt 2 | | | | | | | | |
| Aunt 3 | | | | | | | | |
| Uncle 1 | | | | | | | | |
| Uncle 2 | | | | | | | | |
| Uncle 3 | | | | | | | | |
| RELATIVES – PATERNAL SIDE | | | | | | | | |
| Grandmother | | | | | | | | |
| Grandfather | | | | | | | | |
| Aunt 1 | | | | | | | | |
| Aunt 2 | | | | | | | | |
| Aunt 3 | | | | | | | | |
| Uncle 1 | | | | | | | | |
| Uncle 2 | | | | | | | | |
| Uncle 3 | | | | | | | | |
| Other relative: _____ | | | | | | | | |
| Other relative: _____ | | | | | | | | |

21. Please tell us about any family history reported in the table (Q. 20) above that you are unsure about.

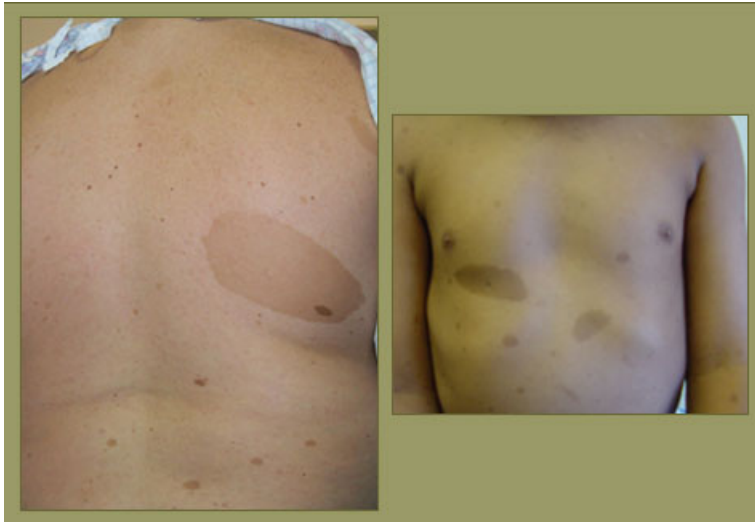
22. Tell us about any other unusual skin conditions that you or any of your family members have now or have had in the past.

23. Tell us about any other general health conditions that either you or any of your family members have now or have had in the past.

24. Let us know if there is anything else you want to tell us about GIST or any other medical conditions in you or your family.

***Thank you for participating in this study!!
Please don't forget to sign and submit your Consent form!***

PICTURE A



PICTURE B



PICTURE C



PICTURE D

