



# ***Your Opinions About Genetic Research?***

This is an anonymous research survey that will help Blood Centers of the Pacific and United Blood Services learn about blood donors' opinions on genetic research and testing. Your participation is voluntary and refusal will not affect your ability to donate blood. You can refuse to answer any or all of the questions. If you have questions, you may contact Dr. Edward Murphy at 415-749-6668. Thank you.

Blood Centers of the Pacific and United Blood Services are considering whether blood donors might participate in genetic studies. If blood donors agree to participate, they would be asked for a sample of blood to be taken during the normal blood donation process and might be asked some additional questions about their health. Donor samples would be frozen in a specimen bank and used for future genetic studies by researchers working with the blood bank. These samples would be stored for an unlimited time. Any results from these studies would not be put in donors' medical records and would not be given to donors' insurance companies.

On the following pages, we describe three different ways or scenarios that blood donors could participate in genetic studies or testing. Please read each scenario and answer the questions that follow it.



## Please read the following instructions before completing the questionnaire

### Instructions

- Please use only black or blue ink or No. 2 pencil.
- Do NOT use felt tip pens or markers.
- Fill in the circle next to your answer completely and write numbers and letters clearly within the boxes:

Correct



| 1 | 9 | 6 | 4 |

Incorrect



| 1 | 9 | 6 | 4 |

### **Example**

- Please fill in only one circle for each question, unless otherwise instructed.
- Please answer each question as best you can – even your best guess or estimate is helpful.
- If you change an answer, be sure to erase or mark out completely.
- To keep the survey confidential, please do not put your name anywhere on this questionnaire.

If you wish to provide additional comments about any of the questions or about this research study, you may use the “Comments” section after many questions.







## Scenario 3 - Genetic Testing Offered as an Optional Service at the Blood Bank

Certain genes are known to increase a person's risk for a particular disease. For example, a group of genes called HNPCC increase a person's risk for colon and rectal cancer and the BRCA gene increases a woman's risk for breast and ovarian cancer. In the future, the blood bank could offer genetic testing for specific genes as an optional service to blood donors, not for research. Donors would receive information about which genetic tests are available as well as the benefits and risks of being tested.

If blood donors agree to genetic testing as a service:

- a small sample of blood would be taken during the normal donation process
- donors would receive test results at a counseling session
- by testing at the blood center, a donor's insurance company would not know about the testing or results
- donors could decide later whether or not the results would be sent to their doctor

1) If the blood bank offered genetic testing for specific genes as an optional service, would you be interested in being tested?

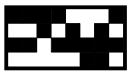
- Yes —————> Go to Question 2
- No —————> Skip to Question 4
- I don't know —————> Go to Question 2

Comments

2) There are genetic tests for diseases that you may develop or that you may pass on to your children. For which diseases would you be interested in testing, if a good genetic test was available?

( mark all that apply )

- Breast and ovarian cancer
- Cystic fibrosis
- Muscular dystrophy
- Prostate cancer
- Colon cancer
- Diabetes
- Heart disease



Draft

Booklet

--	--	--	--

3) What is the maximum amount you would be willing to pay out-of-pocket for a genetic test at the blood bank?

- Nothing
- \$1 to \$49
- \$50 to \$99
- \$100 to \$149
- \$150 to \$199
- \$200 or more
- I don't know

Comments

4) If genetic testing was offered as an optional service when you donated blood, would you be more or less likely to donate blood in the future?

- Much more likely
- Somewhat more likely
- Just as likely
- Somewhat less likely
- Much less likely

Comments



### Additional Information

1) Type of blood donation you are giving today:

- whole blood ( regular )
- platelet pheresis
- plasma pheresis
- directed ( for a friend or relative )
- double red cell ( red cell apheresis )
- autologous ( for yourself )

2) Have you ever donated before today?

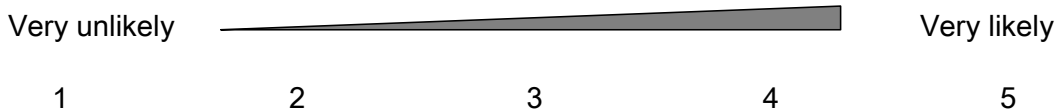
- Yes —————> Go to Question 3
- No —————> Skip to Question 4

3) How many times have you donated in the past five years, including today's donation?

- Once
- Twice
- 3 times
- 4-5 times
- 6-10 times
- 11-20 times
- More than 20 times

4) In the next 6 months, how likely will you be to donate again?

*Please circle a number from 1 to 5: 1=Very unlikely, 5=Very likely*



5) Age:

- 16 to 19 years
- 20 to 29 years
- 30 to 39 years
- 40 to 49 years
- 50 to 59 years
- 60 or more years

6) Gender:

- Male                                   Female



Draft

Booklet 

--	--	--	--

7) Race/ethnicity:

- Caucasian
- African-American
- Hispanic/Latino
- Asian/Pacific Islander
- American Indian/Alaska Native
- Other

8) Five digit ZIP code of primary residence:

*Please fill in the lines below*

--	--	--	--	--

9) Education:

- grade school or less
- some high school
- completed high school
- some college or trade school
- completed college ( bachelor's degree )
- graduate school or higher

Additional Comments

--

***Thank you for your participation***