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# 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 <u>NOT</u> use felt tip pens or markers.
- Fill in the circle next to your answer completely and write numbers and letters clearly within the boxes:

- 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 <u>not</u> 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.



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## Scenario 1 - Blood Donors' <u>Identities Would Be Linked</u> to Their Samples for Genetic Research Studies

When a blood donor donates a sample of blood for genetic research studies, the ID number attached to the sample would allow researchers to know the donor's name and their answers to the health questionnaire. Blood donors could request to have their samples removed from the specimen bank at any time. If the donor agrees to participate in the research, this would:

- allow the blood bank to contact donors if researchers found that a participant had a gene that may increase his or her risk for a certain disease
- allow researchers to conduct certain genetic studies that require follow-up with participating donors
- although the blood bank would protect the donor's identity as it already does in blood collection, there is a small potential risk to the privacy of the donor's genetic test results
- 1) How likely would you be to participate in genetic studies described above in **scenario 1**? *Please circle a number from 1 to 5: 1=Very unlikely, 5=Very likely*

	Very unlikely -				Very likely	
	1	2	3	4	5	
Comments	8					
•	e blood bank asked blood, would you be		=		e in <b>scenario 1</b> when	you
C	Much more likely					
C	Somewhat more lik	kely				
C	Just as likely					
C	Somewhat less like	ely				
C	Much less likely					
Comments	6					



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Very likely

### Scenario 2 - Blood Donors' <u>Identities Would Not Be Linked</u> to Their Samples for Genetic Research Studies

When a blood donor donates a sample of blood and completes a questionnaire for genetic research studies, the sample and questionnaire would <u>not</u> be linked to the donor's name or blood donor ID.

If the donor agrees to participate in the research, this would:

- prevent the blood bank from contacting donors if researchers found that a participant had a gene that may increase his or her risk for a certain disease
- prevent researchers from conducting certain genetic studies that would require follow-up with participating donors
- increase the privacy of the donor's genetic test results
- 1) How likely would you be to participate in genetic studies described above in **scenario 2**? *Please circle a number from 1 to 5: 1=Very unlikely, 5=Very likely*

	, ,				,
	1	2	3	4	5
Comments					

- 2) If the blood bank asked you to participate in genetic studies described above in **scenario 2** when you donated blood, would you be more or less likely to donate blood in the future?
  - O Much more likely

Very unlikely

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

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### 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 <del> </del>	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 )
  - O Breast and ovarian cancer
  - O Cystic fibrosis
  - O Muscular dystrophy
  - O Prostate cancer
  - O Colon cancer
  - O Diabetes
  - O Heart disease



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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
O 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?
O Much more likely
○ Somewhat more likely
○ Just as likely
○ Somewhat less likely
O Much less likely
Comments



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#### **Additional Information**

1)	Type of blood donation	on you are giving to	oday:		
		S	s)		
	○ autologous( fo		,		
2)	Have you ever donat	ed before today?			
	○ Yes ——	Go to Question 3			
	○ No ——	Skip to Question 4	ļ		
3)	How many times have Once O Twice O 3 times O 4-5 times O 6-10 times O 11-20 times O More than 20 times		he past five	e years, i <b>ncluding</b>	today's donation?
•	In the next 6 months			-	
	Very unlikely —				Very likely
	1	2	3	4	5
5)	Age:	nrs			
6)	Gender:				
	○ Male	O Female			



7)	Race/ethnicity:  Caucasian African-American Hispanic/Latino Asian/Pacific Islander American Indian/Alaska Native Other
	Five digit ZIP code of primary residence: ease fill in the lines below
9) addition	Education:  O grade school or less O some high school O completed high school O some college or trade school O completed college ( bachelor's degree ) O graduate school or higher

#### Thank you for your participation