

HEIRS FAMILY POST RESULT FORM

Participant ID	<input style="width: 20px; height: 20px;" type="text"/>	Date of Visit	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	
	<i>[affix ID label here]</i>	Month	Day	Year
Acrostic	<input style="width: 20px; height: 20px;" type="text"/>	Completed by	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	

Please answer **each** question below by marking the one **box** that best describes your opinion. If you are unsure how to answer a question, please give the best answer you

Example Question:

	Yes	No	Not Sure
Have you made a visit to the doctor's office in the last year? <i>(If you <u>have</u> made a visit to the doctor's office, this is how you should fill in the question.)</i>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

1. Who first told you about the HEIRS Study?

- 1 Family member 2 Researcher 3 Other 4 Don't remember

2. How much did you know about hemochromatosis or iron overload BEFORE you were contacted about being in the HEIRS Study?

- 1 Nothing 2 Some 3 A lot

3. Since you first heard about the HEIRS Study, how much have you used each of the following sources to look for additional information about hemochromatosis or iron

- | | | None | Some | A lot |
|--|---|--------------------------|----------------------------|----------------------------|
| 3a. Phone call or written material from the HEIRS Study..... | 1 | <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 3b. Family members..... | 1 | <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 3c. The library..... | 1 | <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 3d. The Internet..... | 1 | <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 3e. Your doctor or other health workers..... | 1 | <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 3f. Other (Specify): | | | | |

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4. Before this study, did you know that there might be hemochromatosis or iron overload in your family?.....

	Yes	No	Not sure
1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

5. Before this study, did you know of any family members who had to donate blood regularly for their health?.....

	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
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6. What is your opinion of the information you received from the HEIRS Study about hemochromatosis and your test results?

	Strongly Agree	Agree	Disagree	Strongly Disagree
6a. I found the information I received to be clear and easy to understand.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
6b. I received enough information.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
6c. I still have questions about hemochromatosis and iron overload or my test results.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
7. In general, I think genetic testing to find out about disease risk is a good idea.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

8. The following statements are about the test results you received. Please answer each item.

	Yes	No	Not sure
8a. I do not have any known hemochromatosis gene variations (mutations).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
8b. I have hemochromatosis gene variations (mutations) in both my hemochromatosis genes.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
8c. I have hemochromatosis gene variations (mutations) in one, but not both of my hemochromatosis genes.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
8d. I do not have iron overload.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
8e. I do have iron overload.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
8f. I have hemochromatosis gene variations (mutations) that may also be present in members of my family.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

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9. What were you told to do in response to your test results?

		Yes	No	Not sure
9a. There were no specific recommendations made to me.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
9b. Talk to my personal physician about my test results.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
9c. Have my personal physician test the amount of iron in my blood about once a year to make sure it is not too high.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
9d. Have my blood drawn to lower the amount of iron in my blood.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
9e. Talk to my family members about their possible risk for hemochromatosis or iron overload.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

		Probably not	Not sure	Probably yes	Does not apply
10. Do you think these recommendations will help your health?	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

11. Do you feel confident that you can follow the recommendations?	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
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12. Please indicate whether and how much you have experienced each statement since you found out about the possible risk of hemochromatosis or iron overload in your

		Never	Rarely	Sometimes	Often
12a. Feeling upset, sad or anxious about the test results in your family.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12b. Feeling relieved that no known hemochromatosis gene variations (mutations) exist in your family.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12c. Feeling a loss of control because of the test results in your family.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12d. Having problems enjoying your life because of the risk in your family.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12e. Worrying about your own risk of developing iron overload or hemochromatosis or having your	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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12. Please indicate whether and how much you have experienced each statement since you found out about the possible risk of hemochromatosis or iron overload in your family. (continued)

		Never	Rarely	Sometimes	Often
12f. Feeling more in control of your future health because of knowing about the test results in your family.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12g. Thinking about the risk in your family has caused problems in your work or family life.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12h. Feeling frustrated that no known hemochromatosis gene variations (mutations) have been found that explain the	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12i. Feeling relieved that the guidelines about how to deal medically with your family's test results are so clear and	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12j. Worrying about the confidentiality of test results in your family.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12k. Feeling that people think your family is not as good as others.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12l. Worrying about the risk to your family members.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12m. Feeling glad that you took part in this research.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

		Strongly Agree	Agree	Disagree	Strongly Disagree
13. Information about a person's genetic risk should be shared with other family members.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

IF you think the information about genetic risk should be shared with family members, please answer the following questions: (If you don't agree, please skip to item 15)

		Strongly Agree	Agree	Disagree	Strongly Disagree
13a. The person who has the genetic risk should share the information directly with family members.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
13b. The doctor of the person at risk should inform family members only if the person at risk gives permission.....	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
13c. The doctor of the person at risk should inform family members if the person at risk will not share the	1	<input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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14. With whom do you think you will share information about your risk for iron overload?

	1	2	3	4
	Would not share	Would definitely share	Would with <u>some</u> but not all	Does not apply
14a. Spouse or partner.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
14b. Children.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
14c. Parents.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
14d. Brothers and sisters.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
14e. Other relatives.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
14f. Close friends.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
14g. Doctor.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
14h. Employer.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

15. How likely are you to:

	1	2	3	4	5
	Very unlikely	Unlikely	Likely	Very likely	Does not apply
15a. encourage your spouse or partner to be tested for risk of hemochromatosis or iron overload?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15b. have prenatal testing of your unborn children for risk of hemochromatosis or iron overload?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15c. have your newborn children tested for risk of hemochromatosis or iron overload?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15d. have your children under 18 tested for risk of hemochromatosis or iron overload?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15e. encourage your adult children to get genetic testing for risk of hemochromatosis or iron overload?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15f. encourage your adult children to get genetic testing before they get married?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15g. encourage your adult children to have genetic testing before they have children?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

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16. Please give us your opinion about why you think people get sick.

	Very important	Somewhat important	Not important	Not sure
16a. Heredity (it runs in your family).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
16b. The environment (water or air pollution).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
16c. Fate or chance (bad luck).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
16d. Psychological factors (such as stress).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
16e. Lifestyle (smoking, drinking, eating a high fat diet).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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

1 Poor 2 Fair 3 Average 4 Good 5 Excellent

18. How TRUE or FALSE is each of the following statements to you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
18a. I seem to get sick a little easier than other people.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
18b. I am as healthy as anybody I know.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
18c. I expect my health to get worse.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
18d. My health is excellent.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

19. These questions are about how you feel and how things have been for you since you found out about your test results.

	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
19a. Have you been a very nervous person?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
19b. Have you felt so down in the dumps that nothing could cheer you up?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>

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19. These questions are about how you feel and how things have been for you since you found out about your test results. (continued)

	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
19c. Have you felt calm and peaceful?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
19d. Have you felt downhearted and blue?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>
19e. Have you been a happy person?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>

20. Compared to other medical conditions, I would rank hemochromatosis as:

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One of the least serious				One of the most serious

21. The following questions are about genetic testing to find out about disease risk. Please check the boxes to indicate how much you agree or disagree with each statement.

<i>I think genetic testing <u>IS</u> a good idea because:</i>	Strongly Agree	Agree	Disagree	Strongly Disagree
21a. There might be a good treatment by the time you developed the disease.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21b. You might not have the gene for the disease and would be reassured.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21c. It is always good to know whatever you can about your health.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21d. You could get frequent medical screening to catch the disease at a curable stage.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21e. You could change to a healthier lifestyle.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21f. There might be gene therapy that could prevent you from getting the disease.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21g. You could share this risk information with family members.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21h. You could prepare better for the future.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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I think genetic testing IS NOT a good idea because:

	Strongly Agree	Agree	Disagree	Strongly Disagree
21i. You might have trouble getting or keeping your health insurance.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21j. You might feel helpless because you can't change your genes.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21k. It could be a problem if an employer, or future employer, found out about your test result.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21l. You could spend a lot of time worrying about something bad that is still in the future.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21m. You might have trouble getting life or disability insurance.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21n. Knowing that you had a gene that put you at risk could make you feel less healthy.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
21o. You could be bringing bad news into your family.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

The following questions are about your opinions and practices in regard to health care in general (not specifically about hemochromatosis).

22. Is there one particular clinic, health center or doctor's office that you usually go to if you are sick or need health advice?

1 Yes 2 No

23. How long has it been since you last visited a doctor for a routine check up?

1 Less than a year 2 1 - 2 years 3 3 - 5 years 4 More than 5 years 5 Not sure

24. Do you know your cholesterol level?

1 I know the exact number 2 I know if it's too high or low 3 I was told but I've forgotten 4 I don't remember having my cholesterol checked

25. Do you use a seatbelt when driving?

1 Always 2 Usually 3 Sometimes 4 Rarely 5 Never

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26. Do you use a sunscreen product?

2

3

4

Yes, all year long

Yes, but only in the summer

Rarely

Never

27. Do you have any of the following types of insurance?

	Yes	No	Don't know
27a. Disability insurance.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
27b. Life insurance policy.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
27c. Health insurance (any type).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

28. If you do have health insurance, who pays most of the cost of the insurance?

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Employer	Government (State/Province)	Me or my family	Don't know	Does not apply

29. Describe your employment status.

1 <input type="checkbox"/> Unemployed	2 <input type="checkbox"/> Self-employed
3 <input type="checkbox"/> Employed by Federal Government	4 <input type="checkbox"/> Employed by State/Province
5 <input type="checkbox"/> Private Employer (50 or fewer employees)	6 <input type="checkbox"/> Private Employer (51 or more employees)

THANK YOU FOR COMPLETING THIS SURVEY

**PLEASE PUT IT IN THE STAMPED, ADDRESSED ENVELOPE
WHICH HAS BEEN PROVIDED AND MAIL TO THE HEIRS STUDY**