

# HEIRS FAMILY ONE YEAR FOLLOW-UP FORM

Participant ID	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%; text-align: center;">□</td> </tr> <tr> <td colspan="10" style="text-align: center; font-size: small;">[affix ID label here]</td> </tr> </table>	□	□	□	□	□	□	□	□	□	□	[affix ID label here]										Acrostic	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%; text-align: center;">□</td> </tr> </table>	□	□	□	□	□	□
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**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 can. Thank you.**

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

**1. In the past year, how much have you used each of the following sources to look for additional information about hemochromatosis or iron overload?**

	None	Some	A lot
1a. Phone call or written material from the HEIRS Study.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
1b. Family Members.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
1c. The library.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
1d. The Internet.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
1e. Your doctor or other health workers.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
1f. Other (Specify): <input style="width: 60%; height: 20px;" type="text"/>			

**2. Now that some time has passed since the beginning of the HEIRS Study, what is your opinion about the information you received about hemochromatosis, iron overload and your test results?**

	Strongly Agree	Agree	Disagree	Strongly Disagree
2a. 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"/>
2b. I received enough information.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

2c. I still have questions about hemochromatosis and iron overload or my test results.....

1  2  3  4

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**Strongly Agree**   **Agree**   **Disagree**   **Strongly Disagree**

**3. In general, I think genetic testing to find out about disease risk is a good idea.....**

1  2  3  4

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

**Yes                      No                      Not sure**

4a. I **do not** have any known hemochromatosis gene variations (mutations).....

1  2  3

4b. I have hemochromatosis gene variations (mutations) in **both** my hemochromatosis genes.....

1  2  3

4c. I have hemochromatosis gene variations (mutations) in **one, but not both** of my hemochromatosis genes.....

1  2  3

4d. I **do not** have iron overload.....

1  2  3

4e. I **do** have iron overload.....

1  2  3

4f. I have hemochromatosis gene variations (mutations) that may also be present in members of my family.....

1  2  3

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

**Yes                      No                      Not sure**

5a. There were no specific recommendations made to me.....

1  2  3

5b. Talk to my personal physician about my test results.....

1  2  3

5c. 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  2  3

5d. Have my blood drawn to lower the amount of iron in my blood.....

1  2  3

5e. Talk to family members about their possible risk for hemochromatosis or iron overload.....

1  2  3

6. Have you followed the recommendations that were given to you regarding hemochromatosis or iron overload?.....

	<b>Yes</b>	<b>Some, but not all</b>	<b>No</b>	<b>Does not apply</b>
1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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7. Do you think that these recommendations are helping your health?.....

	<b>Probably not</b>	<b>Not sure</b>	<b>Probably yes</b>	<b>Does not apply</b>
1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Please indicate whether and how much you have experienced each statement in the past several months.

**Never Rarely Sometimes Often**

8a. Feeling upset, sad or anxious about the test results in your family.....

1  2  3  4

8b. Feeling relieved that no known hemochromatosis gene variations (mutations) exist in your family.....

1  2  3  4

8c. Feeling a loss of control because of the test results in your family.....

1  2  3  4

8d. Having problems enjoying your life because of the risk in your family.....

1  2  3  4

8e. Worrying about your own risk of developing iron overload or hemochromatosis or having your condition get worse.....

1  2  3  4

8f. Feeling more in control of your future health because of knowing about the test results in your family.....

1  2  3  4

8g. Thinking about the risk in your family has caused problems in your work or family life.....

1  2  3  4

8h. Feeling frustrated that no known hemochromatosis gene variations (mutations) have been found that explain the iron overload in your family.....

1  2  3  4

- 8i. Feeling relieved that the guidelines about how to deal medically with your family's test results are so clear and easy to follow..... 1  2  3  4
- 8j. Worrying about the confidentiality of test results in your family..... 1  2  3  4
- 8k. Feeling that people think your family is not as good as others..... 1  2  3  4
- 8l. Worrying about the risk to your family members..... 1  2  3  4
- 8m. Feeling glad that you took part in this research..... 1  2  3  4

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**Strongly Agree**      **Agree**      **Disagree**      **Strongly Disagree**

- 9. Information about a person's genetic risk should be shared with other family members.....** 1  2  3  4

***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 12)***

**Strongly Agree**      **Agree**      **Disagree**      **Strongly Disagree**

- 9a. The **person who has the genetic risk** should share the information directly with family members..... 1  2  3  4
- 9b. The **doctor** of the person at risk should inform family members **only** if the person at risk gives permission..... 1  2  3  4
- 9c. The **doctor** of the person at risk should inform family members **if** the person at risk **will not share the information**..... 1  2  3  4

**10. During the past year, with whom have you shared information about your risk for iron overload?**

**Have shared**      **Have not shared**      **Have shared with some, but not others**      **Does not apply**

10a. Spouse or partner.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
10b. Children.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
10c. Parents.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
10d. Brothers and sisters.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
10e. Other relatives.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
10f. Close friends.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
10g. Doctor.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
10h. Employer.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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***If you shared information about your risk for iron overload with ANY family members, please answer BOTH of the next two questions. If you did NOT share any information with ANY family members, please skip question 11 and GO TO question 12.***

**11. For family members you DID share information with, check the box that best describes WHY you shared information about your risk for iron overload.**

	Strongly Agree	Agree	Disagree	Strongly Disagree
11a. The doctor or genetic counselor suggested it.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
11b. I always share things with the person(s) I told.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
11c. It made me feel better emotionally to get this off my chest.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
11d. I wanted the person to be able to check out their own risk for hemochromatosis and iron overload.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
11e. I would have felt guilty not sharing the information.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

11f. My family tends to talk about and share information about health, illness and medical issues..... 1  2  3  4

11g. I wanted my family to be included in the HEIRS Family Study..... 1  2  3  4

**12. For the family members you DID NOT share information with, check the box that best describes WHY you did NOT share information about your risk for iron overload.**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
12a. No one told me to share information about my test results.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12b. There are certain members of my family I don't talk to	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12c. The people I didn't tell have too many other problems in their lives right now.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12d. The people I didn't tell don't handle stress well.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12e. My family tends not to talk about or share information about health, illness and medical issues.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12f. I didn't feel that I had an obligation to share this information.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

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**12. For the family members you DID NOT share information with, check the box that best describes WHY you did NOT share information about your risk for iron overload.**

**(continued)**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
12g. I would have felt ashamed or embarrassed to let others know.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12h. I don't burden others with my problems.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
12i. No one else has a right to know about my health.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

12j. I didn't think this disease was serious enough to bother my family about it.....

1  2  3  4

**13. In the past year since you received your test results have you:**

- |   | Yes                        | No                         | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|
| 13a. encouraged 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"/> |
| 13b. had 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"/> |
| 13c. had your newborn children tested for risk of hemochromatosis or iron overload?.....  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 13d. had your children under 18 tested for risk of hemochromatosis or iron overload?.....   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 13e. encouraged 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"/> |
| 13f. encouraged your adult children to get genetic testing before they get married?.....  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| 13g. encouraged your adult children to get genetic testing for risk of hemochromatosis or iron overload before they have children?..... | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |

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

- |  | Very important             | Somewhat important         | Not important              | Not sure                   |
|--|----------------------------|----------------------------|----------------------------|----------------------------|
| 14a. Heredity (it runs in your family).....        | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| 14b. The environment (water or air pollution)..... | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| 14c. Fate or chance (bad luck).....                | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |

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**14. Please give us your opinion about why you think people get sick. (continued)**

Very important	Somewhat important	Not important	Not sure
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- 14d. Psychological factors (such as stress)..... 1  2  3  4
- 14e. Lifestyle (smoking, drinking, eating a high fat diet)..... 1  2  3  4

**15. In general, would you say your health is:**

- 1  Poor      2  Fair      3  Average      4  Good      5  Excellent

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

- |  | Definitely true            | Mostly true                | Don't know                 | Mostly false               | Definitely false           |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 16a. 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"/> |
| 16b. 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"/> |
| 16c. 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"/> |
| 16d. My health is excellent.....                               | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

**17. These questions are about how you feel and how things have been for you in the past year.**

- |   | 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           |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 17a. 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"/> |
| 17b. 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"/> |
| 17c. 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"/> |
| 17d. 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"/> |
| 17e. 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"/> |

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

1   
 One of the  
**least** serious

2

3

4

5

One of the  
**most** serious

**19. 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 think genetic testing IS a good idea because:***

**Strongly Agree    Agree    Disagree    Strongly Disagree**

19a. There might be a good treatment by the time you developed the disease.....  
 1     2     3     4

19b. You might not have the gene for the disease and would be reassured.....  
 1     2     3     4

19c. It is always good to know whatever you can about your health.....  
 1     2     3     4

19d. You could get frequent medical screening to catch the disease at a curable stage.....  
 1     2     3     4

19e. You could change to a healthier lifestyle.....  
 1     2     3     4

19f. There might be gene therapy that could prevent you from getting the disease.....  
 1     2     3     4

19g. You could share this risk information with family members.....  
 1     2     3     4

19h. You could prepare better for the future.....  
 1     2     3     4

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***I think genetic testing IS NOT a good idea because:***

- 19i. You might have trouble getting or keeping your health insurance..... 1  2  3  4
- 19j. You might feel helpless because you can't change your genes..... 1  2  3  4
- 19k. It could be a problem if an employer, or future employer, found out about your test result..... 1  2  3  4
- 19l. You could spend a lot of time worrying about something bad that is still in the future..... 1  2  3  4
- 19m. You might have trouble getting life or disability insurance..... 1  2  3  4
- 19n. Knowing that you had a gene that put you at risk could make you feel less healthy..... 1  2  3  4
- 19o. You could be bringing bad news into your family..... 1  2  3  4

**20. During the past year, have you had a problem finding or keeping a job, or in getting a raise or promotion?** 1  Yes 2  No

*If yes*, was the problem related to hemochromatosis or iron overload?

- 1  Yes 2  No 3  Not certain 4  Does not apply

**21. During the past year, have you been turned down as a volunteer for free blood donation?** 1  Yes 2  No 3  Does not apply

*If yes*, was the problem related to hemochromatosis or iron overload?

- 1  Yes 2  No 3  Not certain 4  Does not apply

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**22. During the past year, have you had an insurance policy canceled, or had trouble getting, keeping, or increasing the amount of your insurance?**

**22a. Health insurance policy**

1  Yes

2  No

If **yes**, was the problem related to hemochromatosis or iron overload?

1  Yes

2  No

3  Not certain

**22b. Disability insurance policy**

1  Yes

2  No

If **yes**, was the problem related to hemochromatosis or iron overload?

1  Yes

2  No

3  Not certain

**22c. Life insurance policy**

1  Yes

2  No

If **yes**, was the problem related to hemochromatosis or iron overload?

1  Yes

2  No

3  Not certain

**THANK YOU FOR COMPLETING THIS SURVEY**

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