HEIRS INITIAL SCREENING FORM

Participant ID	☐☐-☐☐☐-☐☐☐☐☐-☐☐ *[affix ID label here]*	Date of Visit	☐☐/☐☐/☐☐
Acrostic	☐☐☐☐☐☐	Completed by	☐☐☐

The frequency of iron overload and its health effects may differ by age, gender, race and ethnicity. Please answer these questions about yourself, so that we can look at these factors in the study.

1. **What is your gender?**   ₁☐ Male   ₂☐ Female

2. **What is your birthdate?** ☐☐/☐☐/☐☐
   Month   Day   Year

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*Please answer **BOTH** questions*

3. **Are you Spanish, Latino, or Hispanic?**
   ₁☐ Yes   ₂☐ No

4. **Which of these broad categories best describes your race?**
   (you may check more than one)

   ₁☐ American Indian or Alaska Native

   ₁☐ Asian

   ₁☐ Black or African-American

   ₁☐ Native Hawaiian or other Pacific Islander

   ₁☐ White or Caucasian

Please tell us how you found out about the study and why you decided to participate, so that we can better interpret the study results.

5. **How did you hear about this study?**

   ₁☐ I came in for a doctor visit or to have my blood drawn, and found out about it.

   ₁☐ I received a phone call or letter from the study, inviting me to participate.

   ₁☐ I came into the clinic or lab with a friend or family member, and found out about it.

   ₁☐ My family member was in this study and told me about it.

   ₁☐ I learned about it in the newspaper, in the community, on the TV, or on the radio.

   ₁☐ Other: (specify) [_____]

6. **Is this the first time you have been asked to participate in this study?**   ₁☐ Yes ₂☐ No

*It is important for us to understand the health of study participants so that we can interpret the study results correctly. Please tell us a little about your health. Please answer **each** question.*

7. Has a doctor ever told you that you have:

7a. Too much iron in your body, iron overload, or hemochromatosis
………………………………………………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

7b. Arthritis
………………………………………………………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

7c. Diabetes
………………………………………………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

7d. Liver disease or liver cancer …………………………………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

7e. Heart failure
………………………………………………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

7f. Fertility problems or impotence
………………………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

8. Have any of your <u>blood relatives</u> had iron overload or hemochromatosis, or been <u>treated</u> by having their blood drawn on a regular basis? (*by blood relatives, we mean parents, grandparents, brothers and sisters, half-brothers and half-sisters, aunts and uncles, and children*)
……………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

9. *For women only:* Are you pregnant, have you been pregnant within the past 3 months, or are you breast feeding?…………………… ₁☐ Yes ₂☐ No ₃☐ Not Sure

The following are questions about your health in general – not related to hemochromatosis.

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

₁☐ Poor   ₂☐ Fair   ₃☐ Average   ₄☐ Good   ₅☐ Excellent

11. How TRUE or FALSE is <u>each</u> of the following statements to you?	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11a. I seem to get sick a little easier than other people.	₁☐	₂☐	₃☐	₄☐	₅☐
11b. I am as healthy as anybody I know …………………	₁☐	₂☐	₃☐	₄☐	₅☐
11c. I expect my health to get worse ………………………	₁☐	₂☐	₃☐	₄☐	₅☐
11d. My health is excellent …………………………………	₁☐	₂☐	₃☐	₄☐	₅☐

12. These questions are about how you feel and how things have been for you during <u>the past 4 weeks</u>.

	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
12a. Have you been a very nervous person?..	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
12b. Have you felt so down in the dumps that nothing could cheer you up? ……………	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
12c. Have you felt calm and peaceful?...........	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

Acrostic ☐ ☐ ☐ ☐ ☐ ☐

	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
12d. Have you felt downhearted and blue?....	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
12e. Have you been a happy person?............	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

The following are general questions about genetic testing to find out about disease risk.

	Strongly Agree	Agree	Disagree	Strongly Disagree
13. Information about a person's genetic risk should be shared with other family members. …………………………….	1 ☐	2 ☐	3 ☐	4 ☐
14. In general, I think genetic testing to find out about disease risk is a good idea. …………………………………………	1 ☐	2 ☐	3 ☐	4 ☐

15. I think genetic testing <u>IS</u> a good idea because:

	Strongly Agree	Agree	Disagree	Strongly Disagree
15a. There might be a good treatment by the time you developed the disease.……………………………………	1 ☐	2 ☐	3 ☐	4 ☐
15b. You could change to a healthier lifestyle to prevent getting the disease.……………………………………	1 ☐	2 ☐	3 ☐	4 ☐
15c. You could prepare better for the future.......................	1 ☐	2 ☐	3 ☐	4 ☐
15d. You could share this information with family members.	1 ☐	2 ☐	3 ☐	4 ☐

16. I think genetic testing IS NOT a good idea because:

	Strongly Agree	Agree	Disagree	Strongly Disagree
16a. You might have trouble getting or keeping your insurance…………………………………………..	1 ☐	2 ☐	3 ☐	4 ☐
16b. You might feel helpless because you can't change your genes…………………………………………	1 ☐	2 ☐	3 ☐	4 ☐
16c. Knowing that you had a gene that put you at risk could make you feel less healthy………………………	1 ☐	2 ☐	3 ☐	4 ☐
16d. You could be bringing bad news into your family….	1 ☐	2 ☐	3 ☐	4 ☐

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

	Very important	Somewhat important	Not important	Not sure
17a. Heredity (it runs in your family)…………………………….	1 ☐	2 ☐	3 ☐	4 ☐
17b. The environment (ex. water or air pollution)…………..	1 ☐	2 ☐	3 ☐	4 ☐
17c. Fate or chance (bad luck)…………………………………..	1 ☐	2 ☐	3 ☐	4 ☐
17d. Psychological factors (ex. stress) ………………………	1 ☐	2 ☐	3 ☐	4 ☐
17e. Lifestyle (ex. smoking, drinking, eating a high fat diet)	1 ☐	2 ☐	3 ☐	4 ☐