HEIRS MEDICAL HISTORY FORM

Participant ID ☐☐-☐☐-☐☐☐☐☐-☐☐ *[affix ID label here]*

Date of Visit ☐☐/☐☐/☐☐ Month Day Year

Acrostic ☐☐☐☐☐☐

Completed by ☐☐☐

Part 1: Symptoms and Signs

Have you experienced or had any of the following during the past 12 months?

1. **Swelling of feet or ankles** 1☐ Yes 2☐ No 3☐ Don't know
2. **Change in skin color** 1☐ Yes 2☐ No 3☐ Don't know
3. **Unexplained weight loss** 1☐ Yes 2☐ No 3☐ Don't know
4. **Abdominal swelling or fluid** 1☐ Yes 2☐ No 3☐ Don't know
5. ***For men only:*** **Trouble having an erection or loss of sexual drive** 1☐ Yes 2☐ No 3☐ Don't know

Have you been repeatedly bothered by any of the following?

6. **Chronic fatigue/weakness** 1☐ Yes 2☐ No 3☐ Don't know
7. **Shortness of breath** 1☐ Yes 2☐ No 3☐ Don't know
8. **Joint stiffness/pain/ache** 1☐ Yes 2☐ No 3☐ Don't know
9. **Excessive thirst** 1☐ Yes 2☐ No 3☐ Don't know
10. **Polyuria (excessive urination)** 1☐ Yes 2☐ No 3☐ Don't know
11. **Unexplained abdominal pain or discomfort** 1☐ Yes 2☐ No 3☐ Don't know
12. **Unexplained confusion or memory loss** 1☐ Yes 2☐ No 3☐ Don't Know

Part 2: Medical History Information

The following are some questions about your medical history. Some of the questions may refer to things that happened or began long ago, and/or certain information may be sensitive for you to answer. However, your input is very valuable to the study; please answer each question to the best of your ability. If you do not understand a question or word, leave the question blank and ask the Interviewer.

Has a doctor ever told you that you have or had any of the following:

13. **Iron overload or hemochromatosis** 1☐ Yes 2☐ No 3☐ Don't know
14. **Anemia (low blood)** 1☐ Yes 2☐ No 3☐ Don't know
15. **Sickle cell anemia** 1☐ Yes 2☐ No 3☐ Don't know
16. **Thalassemia or other inherited anemia** 1☐ Yes 2☐ No 3☐ Don't know
17. **Unusual blood loss (vomiting or coughing up blood, blood in stool, or blood in urine)** 1☐ Yes 2☐ No 3☐ Don't know

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Has your doctor ever told you that you have any of the following?

18. Diabetes

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

18a. Are you taking medicine for this?
1☐ Yes (if yes ➔)
2☐ No

18b. Insulin 1☐ Yes 2☐ No
18c. Pills 1☐ Yes 2☐ No

18d. At what age was this first treated? | | years old

19. Liver disease

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

Which type? (check one box per line)

19a. Fatty liver 1☐ Yes 2☐ No 3☐ Don't Know
19b. Cirrhosis 1☐ Yes 2☐ No 3☐ Don't know
19c. Liver cancer (cancer that started in the liver) 1☐ Yes 2☐ No 3☐ Don't know
19d. Hepatitis
1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

19e. Check all that apply
1☐ Type A 2☐ Type B
3☐ Type C 4☐ Other

20. Thyroid disease (over-active or under-active thyroid) 1☐ Yes 2☐ No 3☐ Don't know

21. Heart failure or weak heart 1☐ Yes 2☐ No 3☐ Don't know

22. Abnormal heart rhythm, heart beat or action/arrhythmia 1☐ Yes 2☐ No 3☐ Don't know

23. Other heart disease or heart attack 1☐ Yes 2☐ No 3☐ Don't know

24. Arthritis 1☐ Yes 2☐ No 3☐ Don't know

25. Osteoporosis (weak, thin, or brittle bones) 1☐ Yes 2☐ No 3☐ Don't know

26. Porphyria cutanea tarda (blistering skin rash made worse by sunlight) 1☐ Yes 2☐ No 3☐ Don't know

27. HIV or AIDS 1☐ Yes 2☐ No 3☐ Don't know

28. Chronic inflammation, chronic infection, autoimmune disease or lupus 1☐ Yes 2☐ No 3☐ Don't know

29. Cancers (other than those starting in the liver)

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

29a. Specify:

30. Chemotherapy or bone marrow transplant 1☐ Yes 2☐ No 3☐ Don't know

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Part 3: Reproductive History *For Women Only – Men skip to question #37*

31. Have you ever seen a doctor for:

31a. Menstrual problems 1☐ Yes 2☐ No 3☐ Don't know

31b. In-between bleeding 1☐ Yes 2☐ No 3☐ Don't know

31c. Early stopping of periods 1☐ Yes 2☐ No 3☐ Don't know

32. Have you ever been pregnant?

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

32a. Number of pregnancies: | |

32b. Number of live births: | |

33. Are you currently pregnant? 1☐ Yes 2☐ No 3☐ Don't know

34. Have you gone through menopause?

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

34a. At what age? | |

35. At what age did you experience menarche (first menstrual period)? | |

36. Have you had a hysterectomy? (Uterus or womb removed)

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

36a. At what age? | |

Part 4: Blood Transfusion and Donation Information

37. Have you ever had blood transfusions?

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

37a. Total number of pints/units in a lifetime? | | |

38. Have you ever donated whole blood at a blood bank?

1☐ Yes (if yes ➔)
2☐ No
3☐ Don't know

38a. How many units in lifetime? | | |

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Part 5: Lifestyle Information

39. Do you get short of breath:

39a. While resting in a chair? 1☐ Yes 2☐ No

39b. When walking on level ground? 1☐ Yes 2☐ No

39c. When walking quickly or uphill? 1☐ Yes 2☐ No 3☐ Never do this

40. Have you ever consumed alcoholic beverages? 1☐ Yes 2☐ No➔ If no go to Q 43

41. How old were you when you first started drinking alcoholic beverages? | |

42. Do you currently drink alcoholic beverages?

1☐ Yes (if yes ➔)

42a. For how many years did you drink alcoholic beverages? | |

2☐ No (if no ➔)

42b. For how many years did you drink alcoholic beverages? | |

42c. What was the usual number of drinks you had per week before you stopped drinking alcoholic beverages? | |

(One drink equals 1 beer, 1 glass of wine, 1 shot of liquor, or 1 mixed drink. Record 0, if less than one drink per week.)

Part 6: Demographics

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

43. What is the highest grade of school you've completed?

1☐ Less than high school 2☐ High school diploma

3☐ Some university, college or vocational training 4☐ College/Univ diploma or degree(BA/BS)

5☐ Post-graduate training

If you were invited to participate as a <u>family member</u> of another participant please answer the following.

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

45. What is your birthdate? | | / | | | / | | |
Month Day Year

46. Are you Spanish, Latino, or 1☐ Yes 2☐ No

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

1☐ North American Indian, Metis, or Inuit

1☐ Asian

1☐ Black (African, Haitian, Jamaican, Somal)

1☐ Native Hawaiian or other Pacific Islander

1☐ White