

HEIRS ANNUAL CLINICAL FOLLOW-UP FORM
For completion by Clinician/Clinic Staff

Participant ID	<input type="text"/> <input type="text"/> - <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> - <input type="text"/> <input type="text"/> <i>[affix ID label here]</i>	Acrostic <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Date of Form	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <small>Month Day Year</small>	Completed by <input type="text"/> <input type="text"/> <input type="text"/>

1. Have you seen this patient since the HEIRS clinical exam on / / ?
1 Yes 2 No Month Day Year
(date inserted by HEIRS staff)

Please record follow-up information as best you can for this HEIRS study participant.

2. What is this patient's current diagnosis?
(check all diagnoses that apply)

- Hereditary hemochromatosis
- Iron overloading anemia
- Other iron overload
- Porphyria cutanea tarda
- Hepatitis
 - Hepatitis B
 - Hepatitis C
 - Other hepatitis
- No iron overload
- Other, please specify →

3. Has the patient died? 1 Yes 2 No

If yes →

2a. Date of death: / /
Month Day Year

2a. Cause of death: _____

4. Has the patient had any of the following?

- | | |
|--|--|
| 4a. Hepatocellular carcinoma or cholangiocarcinoma | 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No |
| 4b. Liver failure | 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No |
| 4c. Liver transplant | 1 <input type="checkbox"/> Yes (if yes →) 2 <input type="checkbox"/> No |
| 3d. Date of transplant: | <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
<small>Month Day Year</small> |

5. Has the patient received any of the following?

- 4a. Liver biopsy 1 Yes 2 No
- 4b. Quantitative phlebotomy 1 Yes 2 No
- 4c. Additional evaluation for iron overload 1 Yes 2 No

6. Was the patient treated by erythrocytapheresis?

If yes, was iron depletion achieved? 1 Yes 2 No 3 Don't Know

7. Please record the most recent results for:

- 7a. Serum Ferritin concentration $\mu\text{g/L}$ 7b. / /
Month Day Year
- 7c. Transferrin Saturation . % 7d. / /
Month Day Year

If the patient has any of the symptoms or conditions below, please tell us how they have changed since the HEIRS Study Exam. If the patient has not had the symptom or condition, please check #4 (N/A-not applicable).

- 8. Iron overload or hemochromatosis** 1 Improved 2 No Change 3 Worsened 4 N/A
- 9. Anemia** 1 Improved 2 No Change 3 Worsened 4 N/A
- 10. Sickle cell anemia** 1 Improved 2 No Change 3 Worsened 4 N/A
- 11. Thalassemia or other inherited anemia** 1 Improved 2 No Change 3 Worsened 4 N/A
- 12. Unusual bleeding** 1 Improved 2 No Change 3 Worsened 4 N/A
- 13 Diabetes** 1 Improved 2 No Change 3 Worsened 4 N/A
- 14. Liver disease** 1 Improved 2 No Change 3 Worsened 4 N/A
- 15. Thyroid disease** 1 Improved 2 No Change 3 Worsened 4 N/A
- 16. Heart failure** 1 Improved 2 No Change 3 Worsened 4 N/A
- 17. Abnormal heart rhythm, heart beat or action/arrhythmia** 1 Improved 2 No Change 3 Worsened 4 N/A

- 18. Other heart disease or heart attack** 1 Improved 2 No Change 3 Worsened 4 N/A
- 19. Arthritis** 1 Improved 2 No Change 3 Worsened 4 N/A
- 20. Osteoporosis** 1 Improved 2 No Change 3 Worsened 4 N/A
- 21. Porphyrria cutanea tarda (blistering skin rash made worse by sunlight)** 1 Improved 2 No Change 3 Worsened 4 N/A
- 22. HIV or AIDS** 1 Improved 2 No Change 3 Worsened 4 N/A
- 23. Chronic inflammation, chronic infection, autoimmune disease or lupus** 1 Improved 2 No Change 3 Worsened 4 N/A
- 24. Has the patient had chemotherapy or bone marrow transplant since the HEIRS clinical exam?** 1 Yes 2 No