

**Annual Clinical Follow-Up Form**

**For completion by Clinician/Clinic Staff**

SID_DI	HEIRS participant ID - de-identified	Char \$11.
dvisit	Date of form (Number of days from given date)	Num 4.
seensince	Q1. Have you seen this patient since the HEIRS the HEIRS clinical exam 1=Yes 2=No	Num 4.
diaghemo	Q2. What is this patient's current diagnosis? (check all diagnoses that apply) Hereditary hemochromatosis	Char \$1.
diagironover	Iron overloading anemia	Char \$1.
diagotherironover	Other iron overload	Char \$1.
diagporphyria	Porphyria cutanea tarda	Char \$1.
diaghep	Hepatitis	Char \$1.
diagnoironover	No iron overload	Char \$1.
Patientdied	Q3. Has the patient died? 1=Yes 2=No	Num 4.
Heptocellular	Q4. Has the patient had any of the following? 4a. Hepatocellular carcinoma or cholangiocarcinoma 1=Yes 2=No	Num 4.
Liverfailure	4b. Liver failure 1=Yes 2=No	Num 4.
Livertransplant	4c. Liver transplant 1=Yes 2=No	Num 4.
Livertransdate	4d. If yes, date of transplant (Number of days from given date)	Num 4.
liverbiopsy	Q5. Has the patient received any of the following? 5a. Liver biopsy 1=Yes 2=No	Num 4.
quanphlebotomy	5b. Quantitative phlebotomy 1=Yes 2=No	Num 4.
addevalironoverload	5c. Additional evaluation for iron overload 1=Yes 2=No	Num 4.

erytreatment                    Q6. Was the patient treated by                    Num 4.  
erythrocytapheresis?  
1=Yes  
2=No

eryirondepleted                If yes, was iron depletion achieved?                Num 4.  
1=Yes  
2=No  
3=Don't Know

Q7. Please record the most recent results for:

serumferritin                    7a. Serum Ferritin concentration µg/L                    Num 6.

serumferritindate                7b. Date                    Num 4.  
(Number of days from given date)

transferrin                        7c. Transferrin Saturation %                    Num 6.

transferrindate                    7d Date                    Num 4.  
(Number of days from given date)

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).

symptironover                    Q8. Iron overload or hemochromatosis                    Num 4.  
1=Improved  
2=No Change  
3=Worsened  
4=N/A

Symptanemia                        Q9. Anemia                    Num 4.  
1=Improved  
2=No Change  
3=Worsened  
4=N/A

symptsickle                        Q10. Sickle cell anemia                    Num 4.  
1=Improved  
2=No Change  
3=Worsened  
4=N/A

symptthalassemia                    Q11. Thalassemia or other inherited                    Num 4.  
1=Improved  
2=No Change  
3=Worsened  
4=N/A

symptbleeding                        Q12. Unusual bleeding                    Num 4.  
1=Improved  
2=No Change  
3=Worsened  
4=N/A

symptdiabetes	Q13. Diabetes 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptliverdisease	Q14. Liver disease 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptthyroiddisease	Q15. Thyroid disease 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptheartfailure	Q16. Heart failure 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptarrhythmia	Q17. Abnormal heart rhythm, heart beat or action/arrhythmia 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptheartattack	Q18. Other heart disease or heart attack 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptarthritis	Q19. Arthritis 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptosteoporosis	Q20. Osteoporosis 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptporphyria	Q21. Porphyria cutanea tarda (blistering skin rash made worse by sunlight) 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.

symptlupus

Q23. Chronic inflammation, chronic  
infection, autoimmune disease or lupus  
1=Improved  
2=No Change  
3=Worsened  
4=N/A

Num 4.

chemotherapy

Q24. Has the patient had chemotherapy  
or bone marrow transplant since the  
HEIRS clinical exam?  
1=Yes  
2=No

Num 4.