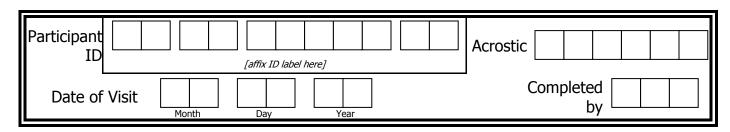
HEIRS ONE YEAR FOLLOW-UP FORM



Please answer <u>each</u> question below by marking the one <u>box</u> that best describes your opinion. If you are unsure how to answer a question, please give the best answer you can. Thank you.

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

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?

		Г	lone	Some	A lot
1a.	Phone call or written material from the HEIRS Study	1		2	
1b.	Family members	1		2	
1c.	The library	1		2	2
1d.	The Internet	1		2	2 <u> </u>
	Your doctor or other health workers	1		2	3
⊥t.	Other (Specify):				

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			Strongly
		Agree	Agree	Disagree	Disagree
	I found the information I received to be clear and easy to understand				
	I received enough information				
2c.	I still have questions about hemochromatosis and iron overload or my test results	1	2	3	4

	Acrostic			
	Strongly Agree	Agree	Disagree	Strongly Disagree
3.In general, I think genetic testing to find out about disease risk is a good idea	-	2	3	4

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

			Yes		No	N	lot sure
4a.	I do not have any known hemochromatosis gene variations	1		2		3	
	(mutations)						
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 bloo about once a year to make sure it is not too high	d1		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
Yes		Some, but no all		No	Does Not apply
Have you followed the recommendations that were given to you regarding hemochromatosis or iron	ź	2	3		4

overload?.....

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6.

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	you think that these recommendations are ping your health?	P I	roba not	-	Not sure	P 1	robably yes		bes not
	ase indicate whether and how much you have ex	xpo	erie	ncec	l each	ı sta	iteme	nt i	n the
pas	st several months.		N	ever	Rarel	v S	ometir	nes	Often
8a.	Feeling upset, sad or anxious about your test results							, ,	⁴
8b.	Feeling relieved that no known hemochromatosis gen variations (mutations) exist in your family	e	1		2	3			1
	Feeling a loss of control because of your test results		L						1
8d.	Having problems enjoying your life because of your terresults	est	. ¹		2	3			1
8e.	Worrying about your risk of developing iron overload hemochromatosis or having your condition get worse.	or	1		2	3			1
8f.	Feeling more in control of your future health		• 1		2	3			1
8g.	Thinking about your test results has caused problems your work or family life				2	3			1
8h.	Feeling frustrated that no known hemochromatosis gevariations (mutations) have been found that explain the	he			2	3			4
8i.	iron overload in your family Feeling relieved that the guidelines are so clear and ea to follow	asy	1		2	3		2	¹
8j.	Worrying about the confidentiality of your test results.		· 1		2	3		2	1
	Feeling that people don't think you are as good as the are					3		2	¹
81.	Worrying about the risk to your family members		• 1		2	3		2	•
8m.	Feeling glad that you took part in this research		• 1 [2	3		2	¹

	Acrostic			
	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

<u>IF</u> you think the information about genetic risk should be shared with family members, please answer the following questions: (if you <u>don't</u> agree, please skip to item 12)

	Strongly Agree		Disagree	Strongly Disagree
9a. The person who has the genetic risk should share the information directly with family members	1	2	3	1
9b. The doctor of the person at risk should inform family members only if the person at risk gives permission	1	2	3 4	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	Have not	with <u>some</u> , but	Does not		
	shared	shared	not others	apply		
10a. Spouse or partner ¹		2	3	1		
10b. Children ¹		2	3	4		
10c. Parents ¹		2	3	4		
10d. Brothers and sisters ¹		2	3	4		
10e. Other relatives ¹		2	3	4		
10f. Close friends ¹		2	3	4		
10g. Doctor ¹		2	3	4		
10h. Employer ¹		2	3	4		

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

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

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

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

		Strongly Agree	Agree	Disagree	Strongly Disagree
a.	No one told me to share information about my test results	1	2		4
b.	There are certain members of my family I don't talk to	1	2		4
	The people I didn't tell have too many other problems in their lives right now				
d.	The people I didn't tell don't handle stress well	1	2		4

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12.For the <u>family members</u> you <u>DID NOT</u> share information with, check the box that best describes WHY you did NOT share information about your risk for iron overload. (continued)

	Agree Agree Disagree Disag	
12e. My family tends not to talk about or share information about health, illness and medical issue	es $2 \square 3 \square 4 \square$	
12f. I don't feel that I had an obligation to share this information		
12g. I would have felt ashamed or embarrassed to let others know		
12h. I don't burden others with my problems		
12i. No one else has a right to know about my health	\cdots 1 2 3 4 2	
12j. I didn't think this disease was serious enough to bother my family about it		

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

		Yes		No		apply
13a.	encouraged your spouse or partner to be tested for risk of hemochromatosis or iron overload?		2		3	
13b.	had prenatal testing of your unborn children for risk of hemochromatosis or iron overload?	1	2		3	
13c.	had your newborn children tested for risk of hemochromatosis or iron overload?	1	2		3	
13d.	had your children under 18 tested for risk of hemochromatosis or iron overload?		2		3	
13e.	encouraged your adult children to get genetic testing for risk of hemochromatosis or iron overload?		2		3	
13f.	encouraged your adult children to get genetic testing before they get married?		2		3	
13g.	encouraged your adult children to get genetic testing for risk of hemochromatosis or iron overload before they have children?		2		3	
	PLEASE GO TO NEXT PAGE					

Does not

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

					Very So		ewhat	t Not		ot
14a.	Heredity (it runs in	your family).		im 1	portant	2 C		importan	nt s	ure
14b.	The environment (water or air p	ollution)	1		2		3	4	
14c.	Fate or chance (bac	d luck)		1		²		3	4	
14d.	Psychological factor	rs (such as st	ress)	1		2 L		3	4 [
14e.	Lifestyle (smoking,	drinking, eat	ng a high fat diet).	1		2		3	4 [
15.In general, would you say your health is:										
	1 Poor	2 Fair	3 Average		4 Go	od		5 Excel	ent	

16.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
16a. I seem to get sick a little easier than other people	1	2	3	4 5	5
16b. I am as healthy as anybody I know	1	2	3	4 5	
16c. I expect my health to get worse	1	2	3	4 5	
16d. My health is excellent	1	2	3	4 5	

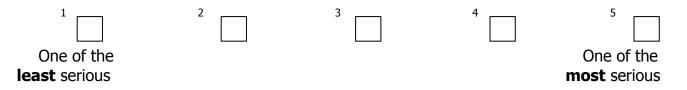
17. These questions are about how you feel and how things have been for you in the past year.

		A	good bi	t				
	All of th	e Most of	of the	Some of A little of None of				
	time	the time	time	the time the time the time				
17a. Have you been a very nervous person?	1	2 3		4 5 6				
17b. Have you felt so down in the dumps that nothing could cheer you up?		2 3		⁴ 5 6				
PLEASE GO TO NEXT PAGE								

17. These questions are about how you feel and how things have been for you in the <u>past</u> <u>year</u>. (continued)

					the time the time	
17c.	Have you felt calm and peaceful?	1	2 3	time	4 5	6
17d.	Have you felt downhearted and blue?	1	2 3		4 5	6
17e.	Have you been a happy person?	1	2 3		4 5	6

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



19.Which of the following health problems are associated with hemochromatosis or iron overload?

		١	Yes		No		Don knov	
19a.	Arthritis-like pain	1		2		3		
19b.	Impotence	1		2		3		
19c.	Painful menstrual periods	1		2		3		
	Prostate or ovarian cancer	1		2		3		
19e.	Heart abnormalities	1		2		3		
	Diabetes	1		2		3		
19g.	Multiple sclerosis	1		2		3		
	Fatigue	1		2		3		
19i.	Asthma	1		2		3		

20.Plea	se answer each question below.		True		False	_	on't 10w
20a.	Too much iron in the blood is always bad	1		2		3	
20b.	In hemochromatosis, iron builds up in the body and causes damage	1		2		3	
20c.	People never die because of hemochromatosis	1		2		3	
20d.	The best way to treat hemochromatosis is to have blood removed until iron levels go back to normal	1		2		3	
20e.	There is no treatment for hemochromatosis	1		2		3	
20f.	People with hemochromatosis can prevent symptoms by drinking 8 glasses of water a day	1		2		3	
20g.	It is not important to treat hemochromatosis until organ damage has occurred	1		2		3	
20h.	A person can have hemochromatosis and not know it	1		2		3	
20i.	A person with hemochromatosis has too much blood, resulting in high blood pressure	1		2		3	
20j.	A gene test can tell you if you already have iron overload	1		2		3	
20k.	Everyone who has variations in their hemochromatosis genes will have too much iron in their blood	1		2		3	
201.	Only white people are at risk for iron overload	1		2		3	
20m	. All variations in hemochromatosis genes increase your risk of	1		2		3 г	

20n. Women tend to develop hemochromatosis earlier in life than men do

having to much iron (iron overload) by the same amount.....

- 200. If someone has hemochromatosis, their brothers and sisters are also at risk for hemochromatosis.....
- 20p. An individual may have one variation in their hemochromatosis¹ genes but others in the same family may have two hemochromatosis genes with variations.....

PLEASE GO TO NEXT PAGE

2

2

2

1

1

3

3

3

21. 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 <u>IS</u> a good idea because:	Strongly Agree	y Strongly Agree Disagree Disagree
21a. There might be a good treatment by the time you developed the disease		$2 \qquad 3 \qquad 4 \qquad \qquad$
21b. You might not have the gene for the disease and would be reassured	1	2 3 4
21c. It is always good to know whatever you can about you health	r^1	2 3 4
21d. You could get frequent medical screening to catch the disease at a curable stage	1	2 3 4
21e. You could change to a healthier lifestyle	1	2 3 4
21f. There might be gene therapy that could prevent you from getting the disease	1	2 3 4
21g. You could share this risk information with family members	1	2 3 4
21h. You could prepare better for the future	1	2 3 4

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I think genetic testing <u>IS NOT</u> a good idea because:

				trongly Agree	Agree	Disagree		ongly agree			
	21i. `	You might have trouble getting or keeping your health insurance	1		23	3	4				
	21j.	You might feel helpless because you can't change your genes	1		23	3	4				
	21k.	It could be a problem if an employer, or future employer, found out about your test result	1		23		4				
	211.	You could spend a lot of time worrying about something bad that is still in the future	1		23		4				
	21m.	You might have trouble getting life or disability insurance	1		23		4				
	21n.	Knowing that you had a gene that put you at risk could make you feel less healthy	1		23		4				
	210.	You could be bringing bad news into your family	1		2 3		4				
22.		ng the past year, have you had a problem finding of or promotion? 1 Yes 2 No	or	keepir	ıg a jol	b, or in (geti	ting a			
	If	yes, was the problem related to hemochromatosis or irc	n	overloa	d?						
		1 Yes 2 No 3 Not certain			4 Does	s not app	ly				
23.		ng the past year, have you been turned down as a tion? 1 Yes 2 No									
	If yes, was the problem related to hemochromatosis or iron overload?										
		1 Yes 2 No 3 Not certain			4 Does	s not app	ly				

			Acrost	ic [
getting, k	e past year, have eeping, or increa Ith insurance pol	ising the amoun				d troul	əle		
If ye	s , was the problem	related to hemoc	ochromatosis or iron overload?						
1 Yes		2 No	3 Not certain						
24b. Disa	ability insurance	policy	ı Yes	2 No					
If ye	s , was the problem	related to hemoc	hromatosis or iron	overlo	oad?				
1 Yes		2 No	3 Not certain						
24c. Life	insurance policy		1 Yes	2 No					
If ye	es , was the problen	n related to hemod	hromatosis or iron	overl	oad?				
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