HEIRS POST RESULT FORM

Participant [affix ID label here]	Acrostic		
Date of Visit/	Com	pleted by	
Please answer <u>each</u> question below by marking the opinion. If you are unsure how to answer a questing you can. Thank you.			-
Example Question:	Y	es No	Not Sure
Have you made a visit to the destar's office	in the last	X 2	3
Have you made a visit to the doctor's office in year?	iii tiie iast 1	2	
year? (<i>If you <u>have</u> made a visit to the doctor's office, this is how</i>	you should fill	in the questi	
year? (If you have made a visit to the doctor's office, this is how Since you first heard about the HEIRS Study, how following sources to look for information about he	you should fill much have yo	<i>in the questi</i> ou used ea	ch of the
year? (If you have made a visit to the doctor's office, this is how Since you first heard about the HEIRS Study, how	yyou should fill much have yo emochromatos	<i>in the questi</i> ou used ea sis or iron (ch of the overload?
year? (If you have made a visit to the doctor's office, this is how following sources to look for information about he la. Phone call or written material from the HEIRS	much have you should fill much have you smochromatos	<i>in the questi</i> ou used ea sis or iron (och of the overload? A Lot
year? (If you have made a visit to the doctor's office, this is how following sources to look for information about he study 1a. Phone call or written material from the HEIRS Study 1b. Family	much have you should fill much have you smochromatos None	<i>in the questi</i> ou used ea sis or iron (och of the overload? A Lot
year? (If you have made a visit to the doctor's office, this is how following sources to look for information about he study 1a. Phone call or written material from the HEIRS Study 1b. Family members	much have you should fill much have you smochromatos None	<i>in the questi</i> ou used ea sis or iron (ach of the overload? A Lot 3
year? (If you have made a visit to the doctor's office, this is how following sources to look for information about he study 1a. Phone call or written material from the HEIRS Study 1b. Family members	much have you should fill much have you smochromatos None	in the question used easis or iron of Some	A Lot 3 3

2a. How do you feel about the way you were FIRST notified about your results?

Letter

Phone Call

			Somewhat		Sc	mewha	at ∖	/ery
		Very Satisfied	Satisfied	Neutral	Dis	ssatisfie	ed Diss	atisfied
		1	2	3		4	5	
			2	3		'	J	
			PLEASE GO	TO NEXT PAG	E			
				А	crostic			
							- 1	1
3.		at is your opinion of nochromatosis and		ou received fr	om the	HEIR	S Study	about
					trongly			Strongly
	3a	I found the information	on I received to be cl		Agree	Agree	Disagree	Disagree
	Ju.	easy to understand		1		2	3	4
	3b.	I received enough			1	2	3	4
		rmation				2	3	7
	3c.	I still have questions	about hemochromato	sis and iron				
		overload or my test re			1	2	3	4
4.	dise	general, I think generals is a good	_		1	2	3	4
5.		following statement h statement.	its are about the t	est results you	u recei	ved. P	lease ans	swer
	5a.	I do not have any ki	nown hemochromato	sis gene	Y	es	No No	t sure
		variations		_	1		2 3	
		(mutations)						
	5b.	I have hemochromat both my hemochrom genes	natosis	(mutations) in	1	2	3	
	5c.	I have hemochromat one, but not both		` '	1	2	3	
	5d.	I do not have iron overload			1	2	3	
	5e.	I do have iron overload			1	2	3	
	5f.	I have hemochromate may also be present		•		2	3	

			Yes	No	Not	sure
6a.	. There were no specific recommendations made to me	1		2	3	
6b.	. Talk to my personal physician about my test results	1		2	3	
6c.	Have my personal physician test the amount of iron in my blood about once a year to make sure it is not too high	1		2	3	
	PLEASE GO TO NEXT PAGE					
	A	crost	tic			
6. Wł	hat were you told to do in response to your test result	ts? ((contin	ued)		
			Yes	No	Not	sure
6d.	. Have my blood drawn to lower the amount of iron in my blood	1		2	3	
6e.	. Talk to family members about their possible risk for hemochromatosis or iron overload	1		2	3	
	Prob no	-	Not sure	Proba yes	-	oes not
yo	you think these recommendations will help ur alth?		2	3		4
	you feel confident that you can follow the commendations?		2	3		4
	ase indicate whether and how much you have experie have received your test results?	ence	d each	state	ment	since
	Ne	ver	Rarely	Some	times	Often
9a.	Feeling upset, sad or anxious about your test results $_1 $		2	3		4
9b.	Feeling relieved that no known hemochromatosis gene variations (mutations) exist in your 1 family		2	3		4
9c.	Feeling a loss of control because of your test results $_1 \[$		2	3		4
9d.	Having problems enjoying your life because of your test 1 results		2	3		4

6. What were you told to do in response to your test results?

	9e.	Worrying about your risk of developing iron overload or hemochromatosis or having your condition get worse	1	2		3	4
	9f.	Feeling more in control of your future health	1	2		3	4
	9g.	Thinking about your test results has caused problems in your work or family life	1	2		3	4
	9h.	Feeling frustrated that no known hemochromatosis gene variations (mutations) have been found that explain the iron overload in your family	1	2		3	4
		PLEASE GO TO NEXT PAG	GE .	Г			
			Acr	ostic			
		se indicate whether and how much you have exp we received your test results? (continued)	erienc				
				Never	Rarely	Sometim	es Often
	9i.	Feeling relieved that the guidelines about how to deal your particular results are so clear and easy to follow	with	1	2	3	4
	9j.	Worrying about the confidentiality of your test results		1	2	3	4
	9k.	Feeling that people don't think you are as good as the are	ey .	1	2	3	4
	91.	Worrying about the risk to your family members		1	2	3	4
	9m.	Feeling glad that you took part in this research		1	2	3	4
		s	Strongly Agree	Aan	D	isagree	Strongly Disagree
10.	Inf	ormation about a person's genetic risk should	Agree	Agre	ee D	visagree	Disagree
	be s	shared with other family members	1	2		3	4
		think information about genetic risk should be sl answer the following questions: (If you <u>don't</u> ag					
	10a	. The person who has the genetic risk should	Strongly Agree	Agre	ee D	isagree	Strongly Disagree
	100	share the information directly with family members	1	2		3	4

10.	Info	rmation about a person's genet	ic risk shou	Strong Agre Ild		Disagree	Strongly Disagree
		hared with other family membe			2	3	4
	10b.	The doctor of the person at risk sl family members only if the person permission	at risk gives	5 _	2	3	4
	10c.	The doctor of the person at risk share the information	sk will not		2	3	4
11.V riskí		whom would you be most likely	to share i	nformatio	on about in		ealth
			Would not share	definitely share	with <u>som</u> not a		Does not apply
	11a.	Spouse or partner	1	2			4
	11b.	Children	1	2	3		4
		PLEASE (GO TO NEX	T PAGE			
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		whom would you be most likely ontinued)	to share in Would not share	nformatio Would definitely share	on about in Would s with <u>some</u> not all	hare <u>e</u> but Do	ealth es not pply
	11c. Parer	nts	1	2	3	4	
	11d.	Brothers and sisters	1	2	3	4	
		Other ves	1	2	3	4	
	11f.	Close friends	1	2	3	4	
	11g. Docto	or	1	2	3	4	
	11h. Empl	oyer	1	2	3	4	

12. How likely are you to:

12a.	encourage your spouse or partner to be tested for risk of hemochromatosis or iron	Very unlikely	Unlikely	Likely	Very likely	Does not apply
	overload?	1	2	3	4	5
12b.	have prenatal testing of your unborn children for risk of hemochromatosis or iron overload?	1	2	3	4	5
12c.	have your future newborn children tested for risk of hemochromatosis or iron overload?	1	2	3	4	5
12d.	have your children under 18 tested for risk of hemochromatosis or iron overload?	1	2	3	4	5
12e.	encourage your adult children to get genetic testing for risk of hemochromatosis or iron overload?	1	2	3	4	5
12f.	encourage your adult children to get genetic testing before they get married?	1	2	3	4	5
12g.	encourage your adult children to get genetic testing before they have children?	1	2	3	4	5
	PLEASE GO TO NE	XT PAG	E			
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13. Plea	se give us your opinion about why you th	nink peo			B1 - 1	N I - 1
			Very important	Somewhat important	Not importa	Not nt sure
	Heredity (it runs in your y)		1	2	3	4
	The environment (water or air tion)		1	2	3	4
	Fate or chance (bad		1	2	3	4
	Psychological factors (such as s)		1	2	3	4
13e.	Lifestyle (smoking, drinking, eating a high fat	diet)	1	2	3	4

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

	1	Poor	2 Fair	3 4	Average	4	Good		5 E x	cellent
15.	How	TRUE or FALSE	is <u>each</u> of the	followin	ng state	ements t	to you?			
						Definitely true	Mostly true	Don't know	Mostly false	Definitely false
	15a.	I seem to get sic	k a little easier th	an other	people	1	2	3	4	5
	15b.	I am as healthy a	as anybody I know	w		. 1	2	3	4	5
	15c.	I expect my healt	th to get worse			. 1	2	3	4	5
	15d.	My health is exce	ellent			. 1	2	3	4	5
		e questions are	_	u feel ar	nd how	things	have be	en for	you <u>sir</u>	<u>ice you</u>
					All of the	Most of A	of the	the	of the	of the
	16a.	Have you been a	a very nervous pe	erson?	time	time 2	time 3	time	time 5	time 6
	16b.	Have you felt so that nothing couup?		nps	1	2	3	4	5	6
		·	PLEASE	GO TO	NEXT	PAGE				
						Α	crostic			
		e questions are	•			things	have be	en for	you <u>sir</u>	<u>ıce you</u>
					All of the time	Most of the time	A good oit of the time	Some of the time	A little of the time	
	16c.	Have you felt ca	lm and peaceful?		1	2	3	4	5	6
	16d.	Have you felt do	wnhearted and b	lue?	1	2	3	4	5	6
	16e.	Have you been a	a happy person?		1	2	3	4	5	6
17 .	Com	pared to other	medical conditi	ions, I v	vould r	ank hen	nochron	natosis	as:	
		1	2	3			4		5	

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

			Yes	No	Don	't Know
	18a.	Arthritis-like	1	2	3	
		pain				
	18b.	Impotence	1	2	3	
		Impotence				
	18c.	Painful menstrual	1	2	3	
		periods				
	18d.	Prostate or ovarian	1	2	3	
	4.0	cancer				
	18e.	Heart abnormalities	1	2	3	
	18f.		1	2	2	
	1011	Diabetes	1	2	3	
					_	
	18g.	Multiple sclerosis	1	2	3	
	18h.	SCIEI USIS		_		
	1011.	Fatigue	1	2	3	
					_	
	18i.	A abbases a	1	2	3	
		Asthma				
		PLEASE GO TO NEXT PAGE				
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10	Dian	as angular angle guartien balaur	7 tel oscie			
19.	Don't	se answer each question below.				
				True	False	Know
	19a.	Too much iron in the blood is always		1	2	3
		bad			- —	
	19b.	In hemochromatosis, iron builds up in the body and cau	ises dama	ge. ₁	2	3
	19c.	People never die because of hemochromatosis		1	2	3

19d.	The best way to treat hemochromatosis is to have blood removed until iron levels go back to normal	1	2		3					
			_		1					
19e.	There is no treatment for hemochromatosis	1	2		3					
19f.	People with hemochromatosis can prevent symptoms by drinking 8 glasses of water a day	1	2		3					
19g.	It is not important to treat hemochromatosis until organ damage has occurred	1	2		3					
19h.	A person can have hemochromatosis and not know it	1	2		3					
19i.	A person with hemochromatosis has too much blood, resulting in high blood pressure	1	2		3					
19j.	A gene test can tell you if you already have iron overload	1	2		3					
19k.	Everyone who has variations in their hemochromatosis genes will have too much iron in their blood	1	2		3					
191.	Only white people are at risk for iron overload	1	2		3					
19m.	All variations in hemochromatosis genes increase your risk of having too much iron (iron overload) by the same amount	1	2		3					
19n.	Women tend to develop hemochromatosis earlier in life than men do	1	2		3					
190.	If someone has hemochromatosis, their brothers and sisters are also at risk for hemochromatosis	1	2		3					
19p.	An individual may have one variation in their hemochromatosis gene but others in the same family may have two hemochromatosis genes with variations	1	2		3					
	PLEASE GO TO NEXT PAGE									
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20. 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			Strongly
20a.	There might be a good treatment by the time you developed the disease	Agree	Agree 2	Disagree 3	Disagree 4
20b.	You might not have the gene for the disease and would be reassured	1	2	3	4
20c.	It is always good to know whatever you can about your health	1	2	3	4
20d.	You could get frequent medical screening to catch the disease at a curable stage	1	2	3	4
20e.	You could change to a healthier lifestyle	1	2	3	4
20f.	There might be gene therapy that could prevent you from getting the disease	1	2	3	4
20g.	You could share this risk information with family members	1	2	3	4
20h.	You could prepare better for the future	1	2	3	4
	I think genetic testing <u>IS NOT</u> a good id	lea becau	se:		
		Strongly			Strongly
20i.	You might have trouble getting or keeping your health insurance	Agree 1	Agree 2	Disagree 3	Disagree 4
20j.	You might feel helpless because you can't change your genes	1	2	3	4
20k.	It could be a problem if an employer, or future employer, found out about your test result	1	2	3	4
201.	You could spend a lot of time worrying about something bad that is still in the future	1	2	3	4
20m.	You might have trouble getting life or disability insurance	1	2	3	4
20n.	Knowing that you had a gene that put you at risk could make you feel less healthy	1	2	3	4

	200.	You could be to family	oringing bad news ir	nto your	1 2 3	4
		,	PLEASE	GO TO NEXT PAGE		
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in g	ener	al (not specifi	ns are about your ically about hemo	chromatosis).	-	
21.		_	cular clinic, healtl need health advic		's office that you	ı usually go to
		1 Yes	2 No			
22.	How	long has it b	een since you last	: visited a doctor f	for a routine che	ck up?
		1	2	3	4	5
	Less	than a year	1 - 2 years	3 - 5 years M	lore than 5 years	Not sure
23.	Do y	ou know you	r cholesterol level	?		
		1	2	3	4	
	I kr	now the exact	I know if it's too	I was told but I've		-
		number	high or low	forgotten	having my choles checked	terol
24.	Do y	ou use a seat	belt when driving	?		
		1	2	3	4	5
		Always	Usually	Sometimes	Rarely	Never
25.	Do y	ou use a suns	screen product?			
		1	2	3	4	
	Yes,	all year long	Yes, but only in	Rarely	Never	
			the summer			

PLEASE GO TO NEXT PAGE

			Acrostic		
26	Do you have any of the following types of	f insurance?	1		
20.	bo you have any of the following types of	i iligarance:	Yes	No	Don't Know
	26a. Disability insurance		1	2	3
	26b. Life insurance policy		1	2	3
	26c. Health insurance (any type)		1	2	3
27.	If you do have <u>health</u> insurance, who pay	s most of th	ne cost of t	he insura	ınce?
	1 2	3	4		5
	Employer Government Me	e or my	Don't kn	iow	Does not
	(State/Province)	amily			apply
28.	Describe your employment status.				
	1 Unemployed	2 Self-er	nployed		
	Employed by Federal Government	4 Emplo	yed by State/	Province	
	Private Employer (50 or fewer employees)	6 Private	Employer (5	1 or more	employees)
29.	What is the highest grade of school you've	e complete	d?		
	1 Less than high school				
	2 High school degree				
	Some university, college or vocational tra	ining			
	Bachelor's degree (BA/BS)				
	Post-graduate training				

THANK YOU FOR COMPLETING THIS SURVEY

PLEASE PUT IT IN THE STAMPED, ADDRESSED ENVELOPE WHICH HAS BEEN PROVIDED AND MAIL TO THE HEIRS STUDY