

CODING CCE RESULTS LETTERS

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"/>	Acrostic	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Date of Results Letter	<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"/>
Person who wrote Results Letter:	<input type="text"/>		

Indicate whether each of the following statements are in the CCE results letter. Mark ALL that apply. If the letter does not have wording that is very close to the wording stated, then mark "No." If you are not sure, mark "unsure." This does not mean there is anything wrong with the letter.

yes no unsure Statement to the effect that...

Biochemical results biochemical data missing

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 1. Your <u>iron levels are normal</u> ("within the normal range", etc.), or you do not have "iron overload." |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 2. You <u>have "hemochromatosis"</u> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 3. You <u>have "iron overload"</u> ("most likely have 'iron overload,'" "results suggest you have 'iron overload'") |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 4. You <u>may have</u> (possibly have, etc.) <u>"iron overload."</u> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 5. You <u>have elevated iron levels</u> (iron levels or test results are "high" or "above" the normal range, too much iron in your blood, etc). |

If yes to 3, 4 or 5, answer items 5a-d. If no, go to #6:

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 5a. ... <u>due to</u> (or maybe due to) <u>"hemochromatosis"</u> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 5b. ... <u>due to</u> (or maybe due to) <u>genes</u> ("changes in" or "mutations of" genes) |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 5c. ... <u>due to</u> (or maybe due to) <u>some other problem</u> (such as liver, bone marrow, sickle cell disease, hepatitis, alcohol use, transfusions, etc.). |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 5d. ... due to <u>unknown reasons</u> . |

Note: If several different reasons are given, mark all that apply. For instance, if **both** genetic **and** other problems are mentioned, mark "yes" for **both 5b and 5c**.

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|--------------------------|--------------------------|--------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 6. Were <u>specific test results</u> for iron levels (<u>transferrin saturation and/or serum ferritin</u>) stated in the letter or mailed with the letter? |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 7. You <u>may develop</u> (are at risk for developing) <u>iron overload in the future</u> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 8. Your <u>iron level(s) are unusually low</u> . |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 9. Some <u>other test result</u> is <u>abnormal</u> or out-of-range. |

yes no unsure

Statement to the effect that...

Genotype results genotype data missing

10. Your **genetic test results were normal** (you do not have any changes, mutations, variants, etc, in your *HFE* or hemochromatosis genes)
11. You **have a genetic mutation/variant/abnormality** (etc.) in (either one or both of) your *HFE* or hemochromatosis gene(s).

If yes, answer 11a-b. If no, go to #12

- 11a. If yes, does the **text of the letter indicate the specific mutation** (C282Y, H63D)
- 11b. Was a **report of the specific mutation(s)** (C282Y, H63D) **attached** to or **included with the letter?**

Management Recommendations

12. You **should** (may wish to, etc.) **share your results with your doctor** (“talk to your doctor about your results”, etc.).
13. You **should** (may wish to, etc.) **have your personal physician measure your iron levels** once a year (or at some other interval) to make sure it is not too high.
14. You **should** (may wish to, etc.) **have your blood drawn** (therapeutic blood drawing, phlebotomy, etc.) to lower the levels of iron in your blood.
15. You **should consider being a voluntary blood donor** several times a year
16. You **should talk to your physician about having a liver biopsy** to see if you have iron overload.

Family Implications

17. Other **members of your family may be at risk** for hemochromatosis (iron overload, too much iron in the blood, etc.).
18. You have **genetic mutations** (variants, abnormalities, etc.) that **may be present in other members of your family.**
19. You should (“may want to,” etc.) **talk to your family members about their possible risk** for hemochromatosis or iron overload (or about your test results or about seeing a doctor).
20. Your **family members should be checked** for (“may want to be tested,” “should/may want to talk to their physician or genetic counselor about,” etc.) **genetic mutations or iron overload** (“changes in their genes,” “iron levels,” etc.).