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POLICY STATEMENT

IRON REPLACEMENT THERAPY IN HHT

Iron deficiency anemia is common in people with HHT with an estimated prevalence of 50%. Further, a number of people with HHT develop symptomatic iron deficiency without anemia. Iron deficiency is an under recognized and sub-optimally managed complication in people with HHT.

We recommend the following guidance for the management of iron deficiency in people with HHT. This guideline is meant to highlight the issues facing HHT patients and to serve as general guidance. The ultimate decision about when to give iron and in what form it should be given may involve other clinical factors not mentioned in this statement:

- All patients with HHT should be maintained in a fully iron-replete state.
- All adults with HHT should have routine monitoring of CBC, transferrin saturation (iron and total iron binding capacity) and ferritin. **The specific interval of this monitoring will be patient-specific and may change as bleeding worsens or improves with hemostatic therapies.**
- A serum ferritin of <50 ng/mL **usually** indicates the need to start iron replacement therapy.
- Oral iron therapy is frequently inadequate and parenteral iron replacement is required to replete iron stores. **Unlike many other etiologies of iron deficiency in which a single IV repletion is adequate, HHT patients requiring IV iron often require regular, ongoing infusions to maintain a ferritin >50 ng/mL and a transferrin saturation >20%.**

- Large amounts of iron may be required to achieve and maintain normal iron levels given ongoing recurrent mucocutaneous bleeding. Although there are a number of iron replacement products, some deliver more iron than others. When possible, treatment plans that allow larger doses of iron to be given are preferable given the frequency and time commitments needed to maintain adequate levels in many HHT patients. Ferric carboxymaltose (Injectafer) should be avoided when possible given its risk of hypophosphatemia. This is particularly important given the fact that people with HHT often need regular iron infusions and repeat iron infusions over time can have a significant negative impact on bone health. If used, it is important to monitor phosphorous levels, especially in patients receiving frequent iron infusions. Pathologic fractures have been reported in HHT patients receiving this form of iron.

Approved by Cure HHT's North American Science and Medical Council – June 2021