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**GUIDANCE FROM THE NORTH AMERICAN  
CURE HHT SCIENTIFIC AND MEDICAL ADVISORY COUNCIL**

**COVID-19**

**Update: 4/22/2021**

**COVID-19 VACCINATIONS & BLOOD CLOTS**

The FDA recently paused use of the Johnson & Johnson COVID-19 vaccine due to reports of rare blood clots observed in 6 patients out of nearly 7 million Americans given this vaccine. Internationally, the AstraZeneca vaccine was also paused due to reports of blood clotting resulting in a risk of 4 in 1 million receiving the vaccine. There have been no recognized associations between the Pfizer or Moderna COVID-19 vaccine and blood clotting.

Given our current knowledge about why the clots may be occurring, there is no reason to believe that patients with HHT who have received any of the following vaccines--Johnson & Johnson, AstraZeneca, Pfizer or Moderna--would be at any increased risk of this complication. The overall safety and efficacy profile of the COVID-19 vaccines approved in the United States is excellent, and COVID-19 is an extremely contagious and potentially deadly disease.

In summary, the risk of developing blood clots WITH COVID vaccines appears to be very rare while the risk of developing blood clots from COVID-19 infection is much higher (ranging between 2-30% in patients hospitalized with the disease). Therefore, for nearly all patients, the benefit of vaccination far outweighs any risk of severe vaccine-associated complications, including blood clots.

**Update: 12/16/2020**

**COVID-19 VACCINATION**

The COVID-19 Vaccine is a major development in the fight against the pandemic. This statement has been developed by the Scientific and Medical Advisory Committee of Cure HHT to answer some of the questions that patients may have.

While the COVID-19 vaccine was not specifically tested in HHT patients, it was tested in patients with chronic diseases. There are no data to suggest that the vaccine will behave differently in HHT than it does in other patient populations. The committee feels that the vaccine should be offered to HHT patients according to CDC guidelines. Possible contraindication for vaccination should be the same as for the general public.

The CDC has recommended that patients with significant underlying illnesses receive the vaccine earlier during initial distribution. While HHT is a chronic disease, the committee feels that the diagnosis of HHT by itself would not place a patient at an increased risk for severe illness. However, there are some patients with HHT and associated co-morbidities that should be considered higher risk and therefore placed into the pool of people to be vaccinated earlier. These would include:

- Patients with **heart failure**
- Patients with **Pulmonary Arterial Hypertension**
- Patients with **Pulmonary AVMs** who experience chronic low blood oxygen levels (Pulse oximetry < 90%)
- **Patients with HHT who frequently access the health care system** which may include those receiving frequent iron infusions, blood transfusions or bevacizumab treatments.

The committee recommends that patients discuss with their physician any concerns they may have regarding vaccination and timing of obtaining the vaccine.

**Update: 4/17/2020**

### **BLOOD CLOTS, COVID-19 AND THE HHT COMMUNITY**

There is growing concern that individuals affected by COVID-19 are at increased risk for thrombotic (blood clot formation) complications and what is referred to as COVID coagulopathy. The incidence of this complication is reported to be as high as 27%.

This increased risk with COVID-19 infections is particularly relevant to patients with HHT who are receiving treatment with medications that are either associated with an increased risk for blood clot formation or interfere with the natural clot disintegration. These medications include: oral agents such as (1) thalidomide, (2) pomalidomide, (3) tamoxifen, (4) pazopanib (Votrient), (5) bevacizumab (Avastin) – intravenous delivery and other antiangiogenic medications, (6) aminocaproic acid (Amicar) and (7) tranexamic acid (Lysteda).

While there is no evidence that HHT confers an increased risk for acquiring the COVID-19 infection, we recommend certain precautions to minimize the risk for complications in patients with HHT who are diagnosed with the COVID-19 infection. They are as follows:

- HHT patients with suspected COVID-19 should alert their treating physician that they have HHT as their diagnosis may be important in any decision to provide prophylactic treatment to prevent clotting;
- HHT patients with suspected COVID-19 should undergo testing to confirm/refute the diagnosis as it has considerable management implications from an HHT standpoint;
- HHT patients with confirmed COVID-19 infection should notify their HHT center/treating physician of this situation promptly;
- HHT patients with confirmed COVID-19 infection should discuss with their prescribing HHT physician the possibility of temporarily discontinuing the following oral medications for 4 weeks: thalidomide, pomalidomide, tamoxifen, pazopanib, and other antiangiogenic medications as well as aminocaproic acid (Amicar), tranexamic acid (Lysteda);
- HHT patients with confirmed COVID-19 infection who are receiving treatment with intravenous bevacizumab (Avastin) should discuss with their prescribing HHT physician the possibility of delaying the next dose of bevacizumab (Avastin) by 4 weeks; and
- HHT patients who are hospitalized with COVID-19 are encouraged to share the contact information of their HHT center with the treating physicians.

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