



Covid-19 and HHT

March 23rd 2020 UPDATE (more versions could follow)

Since COVID 19 is a new virus, there is little published evidence and no information is available yet on the impact that COVID-19 has on HHT patients. **The following information is to help HHT patients understand and orient themselves in this difficult moment.**

Chances of an HHT Patient contracting COVID-19

- **Patients with HHT are not expected to be any more or less susceptible to the COVID-19 virus.** Please remember HHT is not an immunosuppressive disorder.
- **Nosebleed management** could indirectly expose HHT patients to additional risk of contracting the virus so please read carefully: Nearly 95% of patients with HHT have nosebleeds, although of varying magnitude. As they are spontaneous and sudden, handling of the nose is a frequent event and often without previous hygienic precautions. Manipulation of the airway (nose, mouth) without previous hygiene may increase chances of contracting COVID-19. Therefore, it is recommended to sanitize hands before managing nosebleeds even if this implies wasting a few minutes. Once hands are sanitized normal nosebleed management can be performed.

What to keep in mind if an HHT patient contracts COVID-19:

- HHT Patients are mostly in good health, have good life expectancy and **are not expected to have more severe outcomes should they contract COVID-19.**
- Should you present with COVID 19 like symptoms contact your GP or COVID 19 emergency numbers and follow their indications carefully. Trust in your health care system - they will know what is best for you. Avoid presenting in ER facilities unless advised to. This could put you and others at risk.
- An airway infectious disease as COVID -19 could increase epistaxis frequency.

Treatments for HHT patients during COVID 19:

- Elective Treatments will be postponed in most Health Care services. That means that anything not urgent will be suspended. Yet necessary treatments will continue.
- **Anemia:** it is important you keep receiving the necessary therapy, these are not optional. Rest assured you will be getting the care you need. Do not postpone these treatments unless advised to do so by your HHT Center.

Specific manifestations of HHT:

We are aware that the below manifestations of HHT represent a great concern for many patients during this pandemic emergency. In these cases it is advisable, as a precaution, that patients who have the following be extra careful in avoiding contact with the COVID 19 virus:

- **Severe Anemia**
- **Cardiovascular complications due to Liver AVMs**
- **Pulmonary AVMs:** patients with unresolved large pulmonary fistulas that cause chronic hypoxemia (reduction in normal oxygen levels on a regular basis) could be at risk if the oxygen is further reduced due to pneumonia. Please note: small asymptomatic and/or treated lung AVMs do not fall in this category and do not represent an added risk
- **HHT Patients with Pulmonary Hypertension**

Additional information

- Governments across the world are enforcing extreme measures to contain the virus and reduce the number of people who contracted it at a given time. These important measures want to ensure that all people who present severe symptoms can access medical assistance. Your cooperation is paramount for the success of this long term plan to save lives.
- Accurate information on COVID 19 is available through the World Health Organization (www.who.org)
- Follow your National Government and health care websites for specific information on your territory.
- **Reach out to your National HHT Patient Organizations. We are there for you.**

Tips on getting through this emotionally:

- Avoid exposing yourself to an overdose of information - if you feel the need to stay informed make sure you refer to official websites and it is advisable to collect information once a day at the same given time.
- Take care of your body and mind: eat healthy and regularly, exercise and make sure you get regular sleep hours.
- Keep your mind busy: reading, listening to music, cooking, board games, crafts are some of many activities that you can benefit from.
- Keep social contact with friends: phone calls and video calls can help us get through this together.

(Source: The Italian Department of Mental Health)

HHT Europe thanks the following clinicians for their statements on COVID-19 and HHT:

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HHT Europe member websites:

Denmark - <http://hht.dk>

France - <http://amro-hht-france.org>

Germany: <https://www.morbus-osler.de>

Ireland - www.hhtireland.org

Italy - www.hht.it

Italy - www.hhtonlus.org

Netherlands: <https://barteraad.nl/>

Norway - www.osler.no

Spain - <https://www.asociacionhht.org>

Switzerland - www.hhtswiss.org

Friends of HHT Europe

Argentina <https://www.facebook.com/AsociacionArgentinadeFamiliasconHHT/>

Canada - <http://hhtcanada.com>

Finland: <https://hht-osler.fi>

UK - <https://www.hhtuk.org>

USA - www.curehht.org