



MAKE A *DIFFERENCE*

HAE AND THE PANDEMIC – AN UPDATE

FAQs on COVID-19 and vaccination from patients: Possible answers

Disclosure

Prof. Magerl has received financial support from CSL Behring, Shire/Takeda, BioCryst, and KalVista for acting as a study centre investigator during the conduct of clinical studies, and personal fees from CSL Behring, Shire/Takeda, Pharming Technologies, BioCryst, Novartis, Octapharma and KalVista outside of the submitted work.





Frequently asked questions (FAQ)

Questions can be submitted by email, telephone, or personal message services.

Question 1

"My doctor told me that I suffer from an immunodeficiency. Do I have a higher risk to get infected with corona virus?"

As far as can be told today, the risk of getting infected with SARS-CoV-2 is not different in HAE patients than in other people.

Question 2

"As a patient with HAE, is COVID-19 hazardous for me?"

The risk to suffer from a severe course of SARS-CoV-2 infection is related to several factors, like age, male sex and concomitant diseases, like diseases of the cardiovascular system (e.g. coronary heart disease and hypertension), chronic lung diseases (e.g. COPD), chronic kidney and liver diseases, diabetes mellitus, cancer or patients with a weakened immune system (e.g., due to a disease associated with immunodeficiency or due to the regular use of medications that can influence and lower the immune defense, such as cortisone). According to the very limited data at this time, neither the disease HAE nor its treatment is a risk factor for a more severe course of COVID-19 in case of infection.

Question 3

"Can an infection with COVID-19 induce HAE-attacks?"

Infections are known to be potential triggers of HAE-attacks. The same is true for acute SARS-CoV-2 infections. It has been reported that HAE attacks were triggered in HAE patients which were asymptomatic by then (due to prophylaxis or by low basic attack frequency).

Although corona frequently causes infections of the airways, there is no evidence that SARS-CoV-2 infection causes laryngeal HAE swellings.

Question 4

"What should I do after being tested positive for SARS-CoV-2?"

If you have been confirmed to be infected with the SARS-CoV-2 corona virus, you should follow the recommendations of your national health authorities (usually they order isolation/quarantine to avoid further infections). Please be aware that HAE disease activity might increase during the infection. Treat emerging attacks as early as possible with on-demand treatment.



Frequently asked questions (FAQ)

Question 5

“What should I do if I suspect infection with SARS-CoV-2 and while waiting for the test result?”

You should stay at home if you suspect infection and avoid contact with others. Please be aware that HAE disease activity might increase during an infection. Treat emerging attacks as early as possible with on-demand treatment.

Question 6

“My mother suffers from HAE and is in hospital due to severe COVID-19. What should doctors look out for?”

The doctors should know of the HAE disease and should be informed about the current medication (e.g., danazol due its several drug interactions) and contraindicated medication (like ACE-inhibitors). The doctors must know about the risk of induced swellings, especially in the head-neck area, first after intubation and extubation. The administration of short-term prophylaxis is indispensable in these cases.

Question 7

“What about the immunity against SARS-CoV-2 after COVID-19 infection in patients with HAE?”

Infection with SARS-CoV-2 induces the formation of antibodies, which are detectable in the second week after symptom onset. Once released to the blood stream, these antibodies can detect and neutralize corona viruses, thereby leading to immunity. This seems to work in most patients who recovered from COVID-19, but not in all. It remains unclear to what degree the antibodies protect against a second infection with SARS-CoV-2 or a severe course of COVID-19. There is no evidence that the development of immunity against SARS-CoV-2 is impaired in HAE patients.

Question 8

“Can I get my vaccination with HAE?”

Patients with HAE should be vaccinated according to national vaccination schedules. As with all vaccinations, side effects may occur. But apart from a temporary slightly increased risk of developing an HAE attack, HAE patients are not in a higher risk to develop side effects than other persons.



Frequently asked questions (FAQ)

Question 9

“Should I insist on a specific drug for vaccination? “

Several vaccines are in use worldwide. All these vaccines induce immunity via activation of the body’s immune system and subsequent antibody formation. Although data on the vaccines show differences in efficacy and tolerability, all vaccines are basically efficient and well tolerated. There is currently no evidence that one vaccine is more or less efficient or safe for patients with HAE.

Question 10

"My doctor told me that I suffer from an immunodeficiency. Should I get my vaccination earlier?"

C1-Inhibitor deficiency does not affect the immune defense against viruses. Patients with HAE should be vaccinated according to the national vaccination plans.

Question 11

“Do vaccinations worsen HAE?”

As other vaccinations, vaccines for SARS-CoV-2 (regardless the type or the brand) activate your immune system. This effect might result in a somewhat increased risk of a HAE attack for a few days. The effect and the potentially higher risk of attacks is not specific to vaccines for SARS-CoV-2 in general or to a certain brand of vaccine.

Question 12

“As vaccination might induce HAE attacks: Should I abstain from vaccination?”

No, not for this reason. The temporarily increased risk of HAE attacks after vaccination seems to be very small (but not studied) and can be controlled with on-demand treatment.

Question 13

“I have an appointment for vaccination. Should I use short term prophylaxis?”

The temporarily increased risk of HAE attacks after vaccination seems to be very small and can be controlled with on-demand treatment. If you read about swellings in the context of vaccination for SARS-CoV-2, these swelling are a) locally due to an inflammatory injection site reaction or b) due to an allergic reaction. Severe allergic reactions to vaccines for SARS-CoV-2 are very rare (data ranges from 2.5 or 11.1 cases per one million vaccine doses for BNT162b2 (produced by Pfizer-BioNTech) and mRNA-1273 (produced by Moderna Therapeutics)).



Frequently asked questions (FAQ)

Question 14

“I have an appointment for vaccination. Should I adapt my ongoing prophylactic treatment?”

Unless your HAE doctor advises otherwise, we recommend that you continue your current prophylactic treatment when you are about to receive the vaccination. Daily oral treatment should not be interrupted.

In the case of C1-INH replacement, the vaccination should be given close to the last C1-INH injection, but not necessarily on the same day. In the case of lanadelumab prophylaxis, it is recommended to leave a few days between the vaccination and the last lanadelumab injection.

In the case that you participate in a clinical study: Ask your study doctor!

Question 15

“I have an appointment for vaccination. What should I look out for?”

Side effects of the vaccinations are common but usually mild or moderate and last only a few days. Be prepared to feel some pain at the injection site. As an HAE patient, you should carefully monitor your disease activity, be prepared to treat attacks even if you use prophylaxis or usually have only a small number of attacks. You should have at least 2 doses of on demand treatment at home.



Thank you