



Frequently asked questions

The impact of COVID-19 on the medical care of SAID patients

Are SAID patients at a greater risk?

Is there an increased risk of infection for patients with an autoinflammatory disease?

The majority of systemic autoinflammatory disorders (SAID) correspond to disease where the immune system – the system in charge of protecting us against infections – is abnormally activated. Thus, SAID patients are able to fight COVID-19. Of course, SAID may be affected by COVID-19. The risk factors for a severe form of COVID-19 are those of the general population i.e. age > 70 years old, obesity, hypertension and cardiovascular diseases, lung disease either related to SAID or not.

Are patients on biological medications at a higher risk? Are PFAPA patients also included in the increased risk group?

The treatments of SAIDs are mainly immunomodulating or immunosuppressive agents. They have to be discontinued in case of an active infection (including COVID-19). However, several national or international Rheumatology and Paediatric Societies, Rare Disease organizations, as well as patient associations, have proposed consensus statements recommending to continue these therapies during the epidemic period in the absence of infectious symptoms (fever, cough, shortness of breath, diarrhoea). Among all SAID medications, high doses of systemic corticosteroids seem to be the most at-risk treatments.

How big is the risk for a child with DADA2 deficiency on Humira (Adalimumab) therapy?

No answer available to-date in the literature. However, what has been mentioned above for SAID may also apply for DADA2 syndrome patients.

What if patients on biological medications get infected? Should they discontinue biological treatment?

All treatment decisions have to be taken in collaboration with their regular physician. In case of infection, the recommendation is to stop targeted immunotherapies; this also applies to COVID-19. They can be reintroduced after the end of the COVID-19 episode i.e. approx. 4 weeks after COVID-19 first symptoms (when the PCR is negative in almost all patients).

For PFAPA patients taking cortisone once a month, is it safe to keep taking cortisone?

The point should be discussed with the physician in charge of the patient. High doses of systemic corticosteroids can facilitate the development of severe forms of COVID-19, so it might depend on the treatment course and dosage.



Worst-case scenario: Corona + flare. What medications are safe to take?

Every patient is different and there is no clear-cut answer. Thus, such an event needs to be managed with the physician in charge of the patient.

Generally speaking, COVID-19 is the acute and potentially severe condition that needs to be managed before a SAID flare.

Is it true that AID patients should avoid cortisone and Ibuprofen?

Corticosteroids: see above.

There was an alert about NSAID – such as ibuprofen – use in patients starting COVID-19. This has been observed in only one country (France) and not elsewhere in Europe. Thus, the European Medicines Agency did not confirm the alert on NSAID.

If NSAIDs are the key treatment for a specific inflammatory disorder, it is important to speak with the doctor, who will validate NSAID intake in the majority of patients.

For AID patients who have been on cortisone for a long period, should they continue taking it?

People receiving systemic steroids for a long period of time have to continue their therapy to avoid adrenal deficiency. To get more details, please contact your physician.

Is colchicine an immunosuppressant?

No, it is an anti-inflammatory agent. The treatment can be maintained unchanged during the epidemic.

Should I keep going to consultations?

Definitely yes. Doctors have managed to consult or visit their patients with the maximal precautions (barrier measures). Of course, when possible, teleconsultation is an interesting option to avoid public transportation issues at the peak of the outbreak.

What do I do if I am flaring and need medical assistance?

Contact your doctor and if unavailable, go to the Emergency Room of your doctor's hospital.

When the lockdown is over, is it safe for us to go out without having to worry about being infected?

There is no zero risk and it is the same for SAID patients as for the rest of the population.

Outside and in large well-ventilated rooms, the risk of contamination is rather low. The use of masks and hydro-alcoholic solution may help.

To stay in a crowded area or in a room with numerous people for more than 15 minutes, to use public transportation, to attend crowded events, expose you to a higher risk of contamination (as for the general population). In these situations, the use of a facial mask and the frequent use of a hydro- alcoholic solution – as well as all barrier measures – are key to prevent contamination. Such measures have been proven effective in several countries such as South Korea, Hong-Kong and Singapore.

**We hope these answers can help you in staying safe!
Take care of yourself!**

