

# Statement on Alkaptonuria and SARS-CoV-2, Covid-19



aimAKU and DSAKU e.V. are supporting together with MetabERN all patients with rare diseases in the SARS-CoV-2, Covid-19 (corona virus) emergency.

First, we recommend all AKU patients to respect the regulations and guidelines of their health authorities and/or the European Governments have given to all citizens.

Unfortunately, due to lack of knowledge concerning the mechanisms of SARS-CoV-2 viral infection, our scientific and medical staff is unable to give any evidence-based advice to AKU patients. However, AKU patients must be more careful and cautious in their usual behaviour, both with respect to the required isolation as well as for prevention, for the following reasons:

- Covid-19 can apparently progress more severely in patients with an underlying disease.
- There are indications of an increase in infections of all kinds after treatment with nitisinone in AKU, especially at the beginning of treatment. This was an unexpected result in the SONIA 2 clinical trial (which is currently being evaluated for publication and therefore cannot be discussed further here). However, it is necessary to inform people about this new data, as agreed with the regulatory authorities during the start of the clinical trial.

We recommend particular caution and attention to AKU patients who are over 60 years of age (and therefore fall into the highest risk category according to the WHO situation report) or have other additional underlying chronic conditions that put them additionally at increased risk.

There is no reason to discontinue current medication for AKU-related issues.

However, if patients still have concerns related to Covid-19 or are unsure of what to do, they should consult their local GP, following national advice.

As always, the aimAKU and the DSAKU teams will be available to address any AKU-related issues, for specific support and advice.