

Patients with rare skin diseases and COVID-19 virus

ERN-Skin fully supports patients and their families during this period of the COVID-19 pandemic and provides the following recommendations and information for patients with rare skin diseases

FOLLOW CAREFULLY THE GENERAL RECOMMENDATIONS

STRONG RECOMMENDATIONS

- wash your hands regularly
- cough or sneeze into your inner elbow or into a disposable tissue
- avoid touching your mouth, nose or eyes
- wave without shaking hands
- maintain a social distance of 2 m.
- **STAY HOME** and avoid any unnecessary activities
- Keep calm and rational so you will not get exhausted in this current stressful environment
- If you suspect to be infected by COVID-19 virus:
don't hesitate to contact your physician or the specialist

COVID-19 infection is causing:

- **In most cases**, mild to moderate symptoms such as :
sore throat, -dry cough, -flu, -fever,-muscle aches, headache, disordered smell and taste, diarrhea, abdominal pain
- **Possible effects on skin condition:** *rashes, urticaria, pruritus, lesions of toes and fingers*
- **In only a fraction of cases:** a severe progression, with particularly serious acute respiratory distress (ARDS)

Main risk factors of severity currently identified in the general population*

- Respiratory failure*
- Pulmonary arterial hypertension*
- Cardiovascular disease, including hypertension*
- Organ transplantation*
- Renal failure*
- Immunosuppression (condition or medication)*
- Diabetics (uncontrolled, instable)*
- Morbid obesity*
- Patients over 70 years of age*

** knowledge about the COVID-19 progresses weekly and may nuance over time*

COVID-19 PATIENTS INFECTED WITH COVID-19 VIRUS AND A RARE DISEASE OF THE SKIN

FOR ALL PATIENTS WITH A RARE DISEASE OF THE SKIN

-DO NOT MODIFY YOURSELF THE TREATMENT of your chronic disease EVEN if your disease doesn't seem active.

- IF YOU HAVE ANY QUESTION : CONTACT the specialist who manages your treatment

IF YOU HAVE SYMPTOMS SUGGESTIVE OF COVID-19 INFECTION :

- CONTACT your physician +++

- Do not introduce a non steroidal anti-inflammatory drug (NSAID) (ex.: ibuprofen...) without an advice of your physician**

- Paracetamol can be used (Usually Adults: <1g X 3 /day, Children: < 4x 15mg/kg/day)

- **The risk of severe complications** from the infection with the COVID 19 virus **will NOT be increased by the rare disease of the skin IN THE MAJORITY of cases**

- The main risk factors are the same as those in general population

- The instructions to patients are therefore similar to those given to the general population: **please respect the STRONG RECOMMENDATIONS**

***Controversies exist about NSAID and COVID-19. Currently there is no scientific evidence establishing a link between ibuprofen and worsening of COVID-19 infection. More epidemiological studies are expected*

FOR A MINORITY OF PATIENTS WITH A RARE DISEASE OF THE SKIN

Precautions more specific to their disease may arise

This particularly concerns patients taking **immunosuppressive drugs and anti-inflammatory drugs** (*see below****)

that's the case for: auto-immune bullous diseases, auto-inflammatory diseases, some genodermatoses, cancer treatments (eg. kinase inhibitors or immunotherapy)

SUCH PATIENTS HAVE TO :

- BE PARTICULARLY CAUTIOUS about general preventive measures

- NOT MODIFY their chronic treatments by themselves (a relapse of the disease could be more dangerous than the COVID-19 infection)

- NOT introduce new treatments without a medical advice

- TAKE A MEDICAL ADVICE FROM THE SPECIALIST who manages your rare skin disease +++

The following drugs do not make you more vulnerable if you are infected with the COVID-19 virus (alphabetic order)* :

if they have not yet been introduced, please don't do it yourself without a medical advice

Antibiotics
Anti-histaminics
Biologic agents (some of them) (see above****)
Colchicine
Dapsone (in the absence of methemoglobinemia)
Hydroxychloroquine
Intravenous immunoglobulins
Opioids
Paracetamol
Sulfasalazine
Retinoids

***The following drugs make you more vulnerable if you are infected with the COVID-19 virus and receive*

- Jak inhibitors
- Rituximab in the past 1 year
- Ongoing immunosuppressive treatments such as, cyclosporine, cyclophosphamide, azathioprine, mycophenolate mofetil, glucocorticoids doses (like prednisolone > 20mg/day in adults) ****
- Anti cancer drugs
- Biologic agents (eg. Anti TNF blockers)****

* knowledge about the COVID-19 progresses weekly and may nuance over time

**** currently no evidence for an increased risk for/during viral infections with: IL-17-, IL-23-, IL-12/23-blockers, fumaric acid, apremilast, omalizumab, dupilumab, **methotrexate**

ESSENTIAL KEY MESSAGES TO TAKE HOME

Knowledge concerning COVID-19 is in constant progress and information about treatments could be updated according to the international research findings

FOLLOW carefully the general recommendations on preventive measures

DO NOT self-medicate: it can be very dangerous!

DO NOT stop or modify your treatment yourself: a relapse of your disease can be more severe than a COVID-19 infection!

If you have **any questions** relating to COVID-19 virus and your rare skin disease, contact the HCPs of your country for more information +++

These recommendations have been elaborated according to current literature data, recommendations of several scientific societies, and official recommendations of different European countries.

Some controversies remain, that is clearly underlined through the text.

Recommendations could be updated regularly according to the advances of Research and new epidemiological results.

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<https://ern-skin.eu/reference-centers/>



HCP = Health Care Professional