

## COVID-19 and RARE SKIN DISEASES

Newsletter n°1, 24<sup>th</sup> September 2020

Dear all,

We hope that this letter finds you well!

As a reminder, the 'COVID-19 and Rare Skin diseases' European study is ongoing in **56 sites** from the **ERN-Skin** network and also in other **40 sites** from the **FIMARAD** national network.

**18 countries are participating in the study: Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Hungary, Ireland, Italy, Lithuania, Netherlands, Poland, Romania, Spain, Sweden and the United Kingdom.**

We would like to remind you to complete the **online eCRF** via the **link you have received**. If you any have any issues don't hesitate to contact us.

Thank you to those who have already included patients and collected the data! This information reported is helping us understanding the difficulties that you may have faced or questions you may have had while completing the eCRF.

Please note that **some slight modifications were recently implemented in the questionnaire**, mainly in order to specify which assays were performed for the suspicion/diagnosis of COVID-19 infection and to report the result. This in order to also collect the current treatments and those prescribed after the visit (including specific treatments for COVID-19 infection), and to group questions on the same topic.

Since systematic assays (serology, PCR) were performed during the last 3 months in some countries, please report in the eCRF all new information of interest you may have received.

The **pandemic is ongoing**, thus please keep on including in the study also the patients with diagnosed (or suspected) COVID-19 infection that consulted recently.

Could you please also look into your Patients' medical records and evaluate the number of patients presenting with a rare skin disease that you may include in the study (diagnosed or suspected to having COVID-19 infection).

**Please send this estimation to us**, it will help us estimating the number of patients expected to be included in the study and help in refining the overall study duration. Then each site will be contacted to check if the study is proceeding well.

This newsletter is prepared for sharing with you the study update (statistics - asap) and helping you with the completion, if needed. It will be sent once **a month during the next three months**, and **then each two months until the end of the study**.

Will you have any questions regarding the study or the **eCRF completion**, please contact Anna who is in charge of the study (French level) or Catherine (European level).

Best wishes,  
Anna and Catherine

For Prof. Christine Bodemer,  
Coordinator of the ERN-Skin and the FIMARAD network

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