

## COVID-19 and RARE SKIN DISEASES

Newsletter n°2, 19 November 2020

Dear all,

We hope that this letter finds you well!

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.

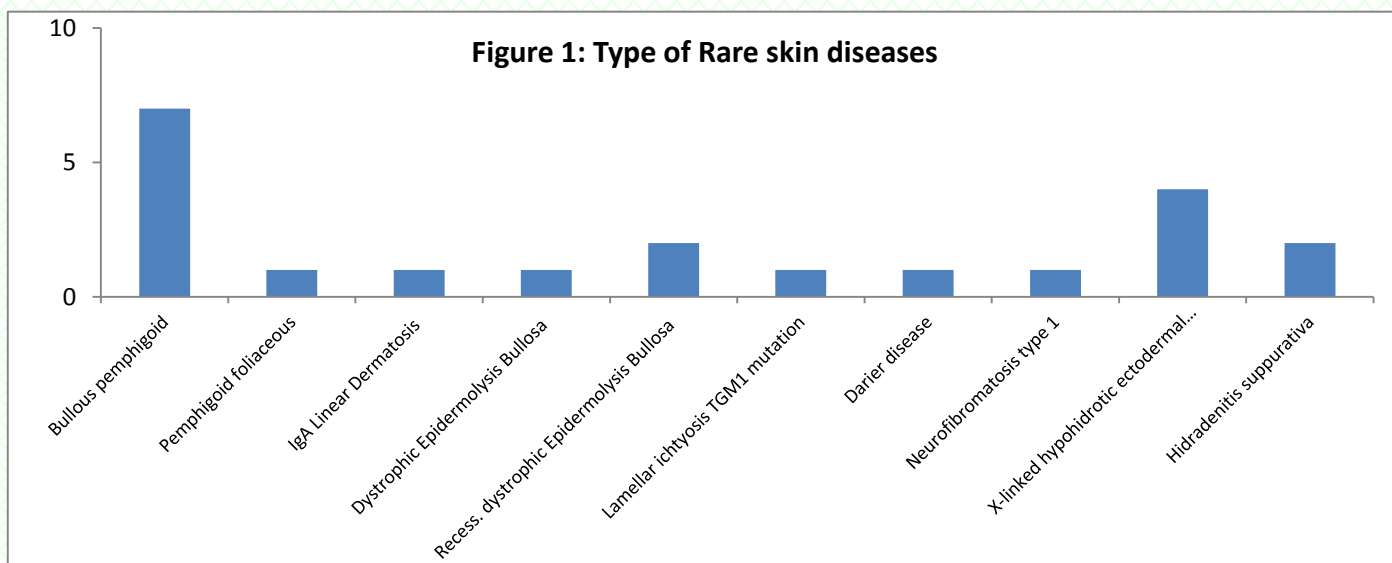
We would like also to remind you to look into your Patients' medical records and evaluate the number of patients presenting with a rare skin disease that you may include in the study (diagnosed or suspected to having COVID-19 infection).

**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. The sites are contacted to check if the study is proceeding well.

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

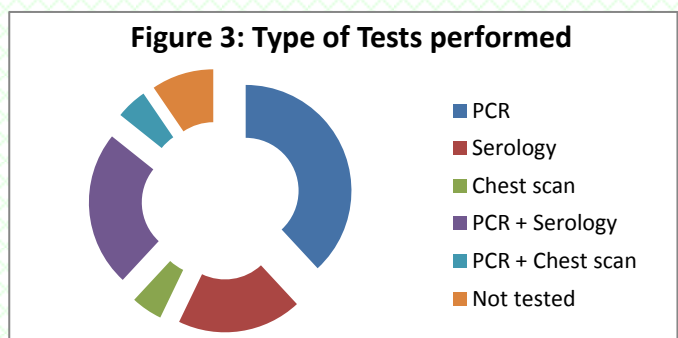
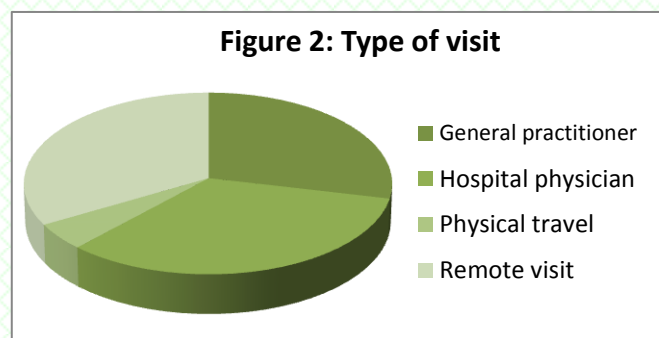
Today, **21 patients** are included in the study: 2 in Lithuania, 2 in Italy, 4 in Germany et 13 in France.

The diseases concerned are the following: Bullous pemphigoid (7/21), X-linked hypohidrotic ectodermal dysplasia (4/21), Dystrophic Epidermolysis Bullosa (2/21), Hidradenitis suppurativa (2/21); the other diseases are presented by 1 patient: Pemphigoide foliaceus, IgA Linear Dermatitis, Recessive Dystrophic Epidermolysis Bullosa, Lamellar ichthyosis with TGM1 mutation, Neurofibromatosis type 1 and Darier disease (Figure 1 below).



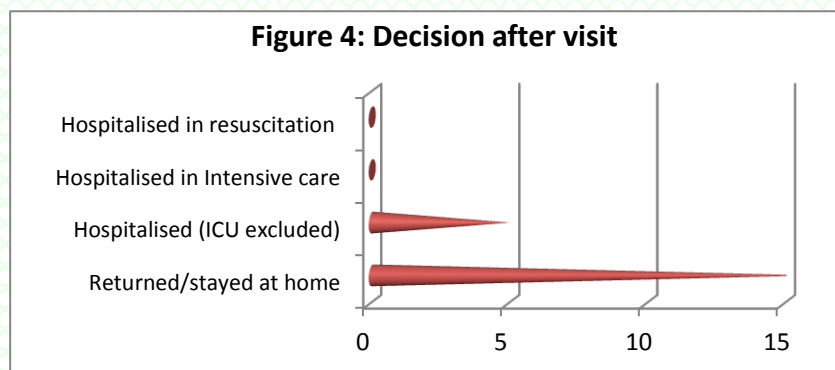
One third of patients visited a General practitioner (6/21), one other third visited a hospital physician (7/21) and one last third consulted a physician remotely (7/21), Figure 2 below.

It has to be noted that one patient was completely asymptomatic. The COVID-19 infection was detected by serology assessment for travel purpose.

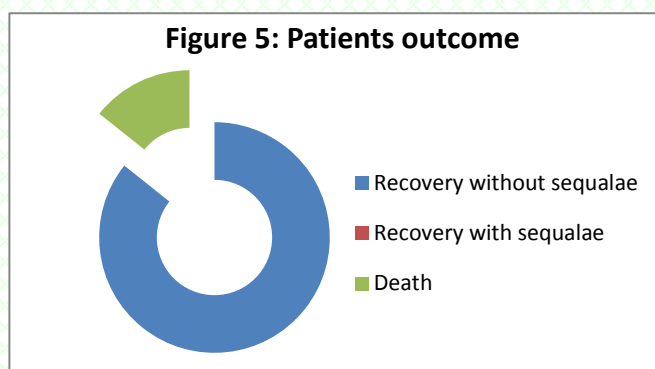


19 patients have been tested for COVID-19 infection (Figure 3 above).  
 The tests were negative for 2 patients (2/19) and positive for all the others (17/19).  
 The PCR was performed for 8 patients, the serology for 4 patients and a chest scan for 1 patient.  
 It has to be noted that 5 patients were tested both by PCR and serology, 3 months apart (3 cases are in Germany),  
 and one patient was tested by PCR and a chest scan was performed, 2 weeks apart.  
 Two patients have not been tested but were considered as infected according the type of their symptoms.

The 3/4 of patients (16/21) returned at home (or stayed at home) after the visit (Figure 4 below).  
 Only 5 patients were hospitalised after the visit; 2 of them died few days after the hospitalisation.



Among the 21 patients included in the study, **18 recovered without sequelae** (Figure 5 below).  
 Three patients presenting with bullous pemphigoid died at 82, 90 and 91 years old, respectively.



Following the resurgence of COVID-19 infection, and since systematic assays (serology, PCR) are still ongoing in European countries, please continue including in the eCRF the data of patients with diagnosed (or suspected) COVID-19 infection that consulted recently, and continue reporting in the eCRF all new relevant information you might have received for the cases already entered.

This newsletter is prepared for sharing with you the study update (statistics, main steps) and helping you with the completion, if needed.

If 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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