

## COVID-19 and RARE SKIN DISEASES

Newsletter n°4, 8<sup>th</sup> June 2021

Dear all,

We hope that this letter finds you well!

Thank you to those who have included patients and collected the data!

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.

**Please note that, since the pandemic is still continuing, the study has been expanded for one year.**

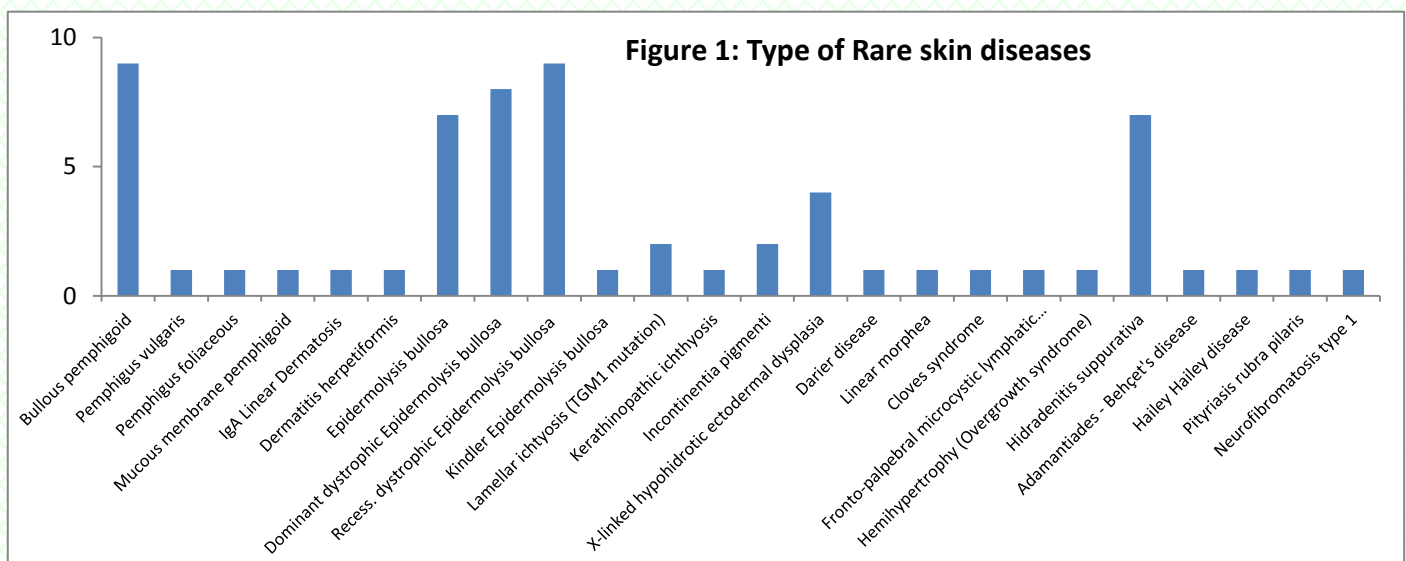
**The monitoring is ongoing and the queries will be sent regularly.**

If needed, the sites will be contacted to discuss and validate the answers, and check if the study is proceeding well.

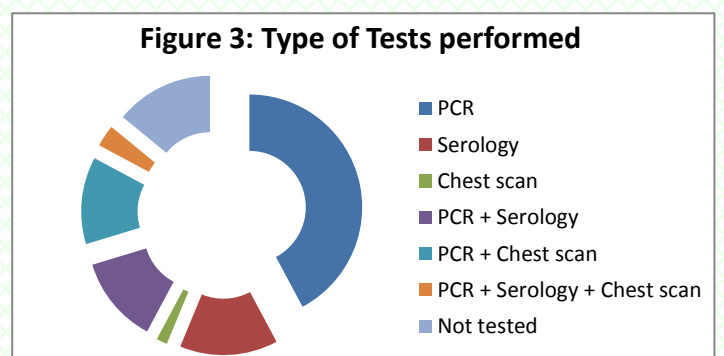
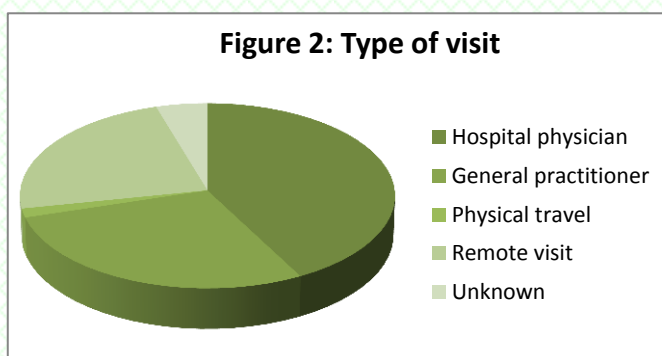
**64 patients** are included in the study: 5 in Germany, 6 in Czech Republic, 8 in Italy, 11 in Lithuania and 34 in France.

The diseases concerned are the following: Bullous pemphigoid (9/64), Recessive dystrophic Epidermolysis bullosa (9/64), Dominant dystrophic Epidermolysis bullosa (8/64), Epidermolysis bullosa (7/64), Hidradenitis suppurativa (7/64), X-linked hypohidrotic ectodermal dysplasia (4/64), Lamellar ichthyosis (2/64) and Incontinentia pigmenti (2/64).

The other diseases are presented each by 1 patient: Pemphigus vulgaris, Pemphigus foliaceus, Mucous membrane pemphigoid, IgA Linear Dermatitis, Dermatitis herpetiformis, Kindler Epidermolysis bullosa, Keratinopathic ichthyosis, Darier disease, Linear morphea, Cloves syndrome, Microcystic lymphatic malformation, Hemihypertrophy (Overgrowth syndrome), Adamantiades - Behçet's disease, Hailey Hailey disease, Pityriasis rubra pilaris and Neurofibromatosis type 1 (Figure 1 below).



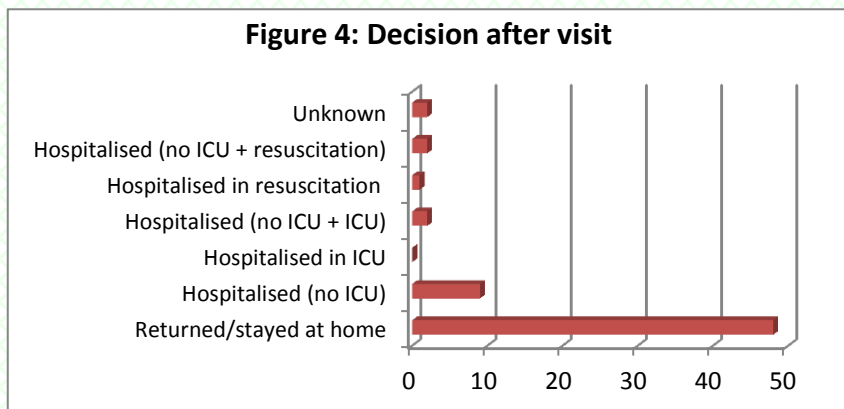
A large majority of patients visited a hospital physician (42%: 27/64), 28% visited a General practitioner (18/64) and 23% consulted a physician remotely (15/64). The type of visit is unknown for 5% of patients (6/64), Figure 2 below. It has to be noted that one patient was detected positive by serology assessment for travel purpose.



55 patients have been tested for COVID-19 infection (Figure 3 above).

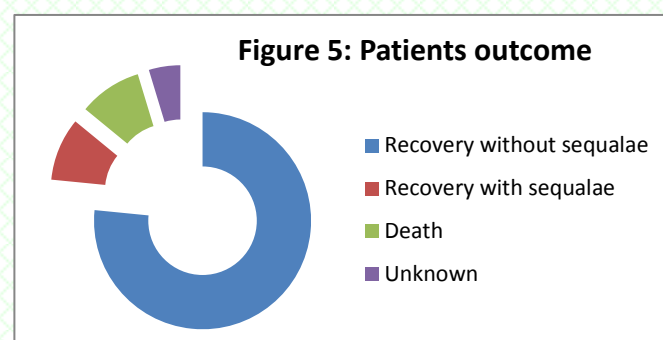
The tests were negative for 5 patients (9.1%), unknown for one (1.8%) and positive for all the others (49/55: **89.1%**). A single test was performed: by PCR for 27 patients (**42.2%**), by serology for 9 patients and a chest scan for 1 patient. 8 patients were tested both by PCR and serology 3 months apart and 8 patients were tested by PCR and a chest scan was also performed. It has to be noted that 2 patients were tested by PCR, serology and a chest scan has been done. Nine patients have not been tested but 4 were considered as infected according the type of their symptoms.

After the visit,  $\frac{3}{4}$  of patients (**75%: 48/64**) returned at home (or stayed at home) and 14 patients (21.9%) were hospitalised: 9 in regular stay (14.1%), 2 in ICU (3.1%) and 3 spent few days in resuscitation and died (4.7%). The decision after the visit was unknown for 2 patients (Figure 4 below).



Among the 64 patients included in the study, more than  $\frac{3}{4}$  **recovered without sequelae (76.6%: 49/64)**.

Six patients died: 5 with bullous pemphigoid aged over 80 years old and one with epidermolysis bullosa. The outcome was unknown for 3 patients (Figure 5 below).



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,  
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