www.
col7a1.
org

International dystrophic eb Patient Registry

International registry of patients with dystrophic epidermolysis bullosa and database of associated COL7A1 mutations

Patient consent form

This form can be used for obtaining informed consent from patients with dystrophic epidermolysis bullosa before including their detailed phenotypic and genotypic data in the online International Dystrophic Epidermolysis Bullosa Patient Registry.

I, the undersigned, hereby declare I have no objection to detailed information about my* disease ("the phenotype"), the results of immunofluorescence and/or electron microscopy studies performed on a biopsy of my* skin (if performed), and the results of analysis of the *COL7A1* genes in my* DNA ("the genotype") being submitted to the International DEB Patient Registry (www.col7a1.org).

I declare that I have been fully informed by my doctor and that

- I understand that data stored in the International DEB Patient Registry are made anonymous. My* name will not be stored in the registry. My* identifier in my local hospital will be used in the registry. Only my doctor knows that this identifier belongs to me*. ☐
- My* doctor will share this identifier with me, so I can view what information about me* is online at www.col7a1.org. ☐
- This information will be details about my* disease and the results of studies on a biopsy of my* skin (if performed) and my* DNA (details on page 2). ☐
- I was able to make a free decision about including my* data in the International DEB Patient Registry and was given enough time to make my decision. I know that I can withdraw my permission at any time by contacting my doctor. My* doctor will then contact the curator of the registry who will completely remove my* information. ☐
- I will be given a copy of the completed and signed form. ☐

** Replace by "my child's" in case you are consenting for a child.*

I give consent for *(please check correct box)* ☐ myself ☐ my son/daughter

Name: .....

Born: ..... (day) ..... (month) ..... (year)

City: ..... Country: .....

Date: ..... (day) ..... (month) ..... (year)

My name: .....
(If giving consent for a child)

Signature:

Part to be filled in by doctor/physician

I declare I have fully informed the above patient/parent/guardian about the issues stated in this form.

Date: ..... (day) ..... (month) ..... (year)

Name: .....

Function: .....

Institution: .....

.....

Patient Identifier: .....

Signature:

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Details about my disease that will be included in the database

Diagnosis: ……

Local patient identifier: ……..

Characteristics
▪ Age
▪ Gender
▪ Ethnicity
▪ Deceased
o If yes, cause of death
▪ Status of MMP1 alleles

Cutaneous
▪ blistering
▪ location
▪ hands
▪ feet
▪ arms
▪ legs
▪ proximal body flexures
▪ trunk
▪ mucous membranes
▪ skin atrophy
▪ milia
▪ nails dystrophy
▪ albopapuloid papules
▪ pruritic papules
▪ alopecia
▪ squamous cell carcinoma(s)
▪ revertant skin patch and reversion mechanism

Extracutaneous
▪ flexion contractures
▪ pseudosyndactyly (hands)
▪ microstomia
▪ ankyloglossia
▪ swallowing difficulties/dysphagia/ oesophagus strictures
▪ growth retardation
▪ anemia
▪ renal failure
▪ dilated cardiomyopathy