

Dear Sir/Madam,

You recently had a consultation in an ERN-Skin Reference Centre. The ERN-Skin gathers together 56 Reference Centres located in 18 European countries. (<https://ern-skin.eu/about-the-ern-skin/>). They aim to improve diagnosis, medical care, social care and information for all patients with the same disease you have, in all Centres, in all European countries.

The purpose of this questionnaire is to improve the quality of care in each Centre of the ERN network and to avoid inequalities of care and patient follow - up at the European level. It is strictly anonymous.

**Thank you very much.**

**1-General Information**

Who was the consultation for?  Yourself  Your Child  Someone (child or adult) you are caring for

Which country was your consultation carried out in?

Ireland

Which country was your consultation carried out in?

Children’s Health Ireland, Crumlin, Dublin

Which country was your consultation carried out in?

Luxembourg

Which country was your consultation carried out in?

Hospital center of Luxembourg

Which country was your consultation carried out in?

Malta

Which country was your consultation carried out in?

Mater dei hospital, Sptar Mater dei hospital, Msida

Which country was your consultation carried out in?

United Kingdom

Which country was your consultation carried out in?

Barts Health NHS Trust, The Royal London Hospital, London

Birmingham Children’s Hospital NHS Foundation Trust, Steelhouse Lane, Birmingham

Guy’s and St Thomas’ NHS Foundation Trust, St Thomas’ Hospital, London: Specialised Service for AIB

Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London

NHS Tayside, Ninewells Hospital & Medical School, Dundee, Scotland

Guy’s and St Thomas’ NHS Foundation Trust, St Thomas’ Hospital, London : Specialised Services for ichthyoses, palmoplantar keratodermas and ectodermal dysplasias

Cardiff and Vale University Health Board - Bwrdd Iechyd Prifysgol Caerdydd a’r Fro, University Hospital of Wales, Heath Park, Cardiff, Wales

Guy’s and St Thomas’ NHS Foundation Trust, St Thomas’ Hospital, London: Highly Specialised Service for Xeroderma Pigmentosum

What was the reason for consulting the Centre?  1<sup>st</sup> appointment  Follow-up  other, please specify.....

Who referred you to this service?

Family doctor  Local dermatologist

Hospital dermatologist (or other medical service)  Someone else, please specify: .....

**2-Consultation and Follow-up** Scale from 0 to 3, 0=no, not at all; 1=just a little; 2=yes, but incompletely; 3=yes and completely;

N.A. = Not Applicable

	0	1	2	3	N.A
Was it easy to find the contact information for the Centre and/or make an appointment?					
Was the consultation adequate from an emotional/psychological point of view?					
Were the location and space of consultation adapted to your specific needs and/or disability (dressing, solar filter, water points, etc.)?					
Was it a multidisciplinary consultation (seeing different specialists during the same consultation or the same day)?					
Did the consultation clearly propose psychological support?					
Did you feel the consultation considered all the necessary specialists to address your care?					
Did you understand the explanations and consequences of the rare disease?					
Do you feel well informed about the disease?					

Satisfaction questionnaire patient consultation

In the case of a genetic disease, were you adequately informed regarding the inheritance risks?														
In the case of a genetic disease, were you referred to a specific genetics consultation?														
Are you satisfied with the follow-up within the Centre?														
Are you satisfied with the information on how to contact the Centre in case of emergency?														
Did you receive any information about the availability of peer support, such as disease specific national patient organisation and/or an international network and/or a national rare disease alliance?														
Has the Centre set up a local network for your follow-up?														
	0/No											3/Yes	N.A.	
In the case of a local network, it includes psychological follow-up														
In the case of a local network, it includes your local doctor														
In the case of a local network, it includes a nurse														
In the case of a local network, it includes social workers														
In the case of a local network, it includes other members (Please specify.....)														
<b>3-Treatment prescription and Therapeutic research</b> Scale from 0 to 3, 0=no, not at all ; 1=just a little ; 2=yes, but incompletely ; 3= yes and completely ; N.A. = Not Applicable	0	1	2	3										N.A.
If a treatment already exists for the disease you consulted for, was the aim of the prescribed treatment discussed?														
Were alternative treatments discussed?														
Were side-effects/intensity/risks of treatment discussed?														
Were you given a specific contact in case of problems regarding at-home treatment?														
Do you know if therapeutic research protocols exist for the disease, or its symptomatic manifestations, in the centre where you consulted?														
<b>4-Global satisfaction</b> Scale from 0 to 10, 0=no, not at all ; 10= yes and totally ; N.A. = Not Applicable	0	1	2	3	4	5	6	7	8	9	10			N.A.
Are you satisfied with how the multidisciplinary team took care of you?														
Are you satisfied with the hospital where the centre is located (premises, signage, reception, lift, etc.)?														

Please add any other comments you may feel useful or necessary:

Thank you!

Max Score of satisfaction: 92