

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

In quale centro è stata effettuata la tua consultazione?

☐ Austria

- ☐ AT01 - EBHaus
- ☐ AT04 - Medical University of Innsbruck

☐ Belgium

- ☐ BE04 - Erasme Hospital
- ☐ BE06 - University Hospital Ghent
- ☐ BE10 - University Hospital Leuven

☐ Czech Republic

- ☐ CZ03 - Hospital Na Bulovce - University Hospital Bulovka
- ☐ CZ04 - University Hospital Královské Vinohrady
- ☐ CZ06 - Saint Anna University Hospital in Brno
- ☐ CZ08 - University Hospital Brno - EB Centrum CR

☐ Germany

- ☐ DE03 - Klinikum der Universität München
- ☐ DE19 - Universitätsklinikum Regensburg
- ☐ DE20 - Städtisches Klinikum Dessau
- ☐ DE24 - Universitätsklinikum Erlangen
- ☐ DE25 - Universitätsmedizin Rostock
- ☐ DE26 - Universitätsklinikum Münster
- ☐ DE27 - Universitätsklinikum Würzburg
- ☐ DE38 - Universitätsklinikum Freiburg
- ☐ DE38 - Universitätsklinikum Freiburg - Genetics

☐ Denmark

- ☐ DK03 - Odense University Hospital
- ☐ DK04 - Zealand University Hospital

☐ Spain

- ☐ ES05 - Hospital Clínic i Provincial de Barcelona y Hospital de Sant Joan de Déu

☐ Finland

- ☐ FI01 - Helsinki University Hospital

☐ France

- ☐ FR09 - Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades
- ☐ FR15 - Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor
- ☐ FR22 - CHU Bordeaux / / Reference Centre for Congenital Anomalies and Malformations SOOR
- ☐ FR28 - CHU de Nice
- ☐ FR31 - CHU de Rouen
- ☐ FR34 - CHU de Toulouse

☐ Croatia

- ☐ HR01 - University Hospital Centre Zagreb

☐ Hungary

- ☐ HU01 - University of Debrecen
- ☐ HU03 - Semmelweis University
- ☐ HU04 - Szent-Györgyi Albert Medical Center, University of Szeged

☐ Ireland

- ☐ IE01 - Children's Health Ireland at Crumlin - non rep

☐ Italy

- ☐ IT04 - Spedali Civili di Brescia
- ☐ IT07 - AO Padua
- ☐ IT09 - Fondazione IRCCS Casa Sollievo della Sofferenza San Giovanni Rotondo
- ☐ IT11 - AOU Bologna
- ☐ IT14 - AOU di Modena
- ☐ IT20 - AOU Città della Salute e della Scienza di Torino
- ☐ IT27 - ASL Tuscan Centre
- ☐ IT33 - Fondazione Policlinico Universitario A. Gemelli Rome
- ☐ IT34 - Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic Milan
- ☐ IT39 - Fondazione IRCCS IDI Luigi Maria Monti – Rome
- ☐ IT53 - AOU Meyer di Firenze
- ☐ IT58 - Pediatric hospital Bambino Gesù, Rome

☐ Lithuania

- ☐ LT04 - Hospital of Lithuanian University of Health Sciences Kauno Klinikos

☐ Luxembourg

- ☐ LU01 - Affiliated Partner - Centre Hospitalier du Luxembourg

☐ Latvia

- ☐ LV01 - Children's clinical university hospital, Riga, Latvia

☐ Malta

- ☐ MT02 - Affiliated Partner - Mater Dei Hospital

☐ Netherlands

- ☐ NL01 - Academic Medical Center Amsterdam
- ☐ NL02 - University Medical Centre Groningen
- ☐ NL03 - Erasmus MC University Medical Center Rotterdam
- ☐ NL06 - Maastricht University Medical Center
- ☐ NL13 - University Medical Center Utrecht

☐ Romania

- ☐ RO02 - Colentina Clinical Hospital

☐ Sweden

- ☐ SE05 - Uppsala University Hospital

☐ Slovenia

- ☐ SI02 - Clinical institute for genomic medicine, university medical centre Ljubljana

What was the reason for consulting the Centre?

- ☐ 1st 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?					
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 _____)			

**3-Treatment prescription and Therapeutic research** 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?					

**4-Global satisfaction** 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