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DELIVRABLE 11: ERN-SKIN PATIENT EDUCATION PROGRAMMES AND TOOLS

ERN-Skin

Specific Agreement number: 838437 — ERN-Skin — HP-ERN-SGA-2018

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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DOCUMENT INFORMATION

DELIVERABLE 11: ERN-SKIN PATIENT EDUCATION PROGRAMMES AND TOOLS

ERN: ERN-Skin

Call: Specific Agreement number: 838437 – ERN-Skin – HP-ERN-SGA-2018

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Short Description

Patient education programmes and tools accredited by the ERN-Skin

DISSEMINATION LEVEL

PU	Public	✓
IN	Internal use only	
CO	Confidential, only for members of the consortium (including Commission Services)	

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INTRODUCTION

According to the World Health Organisation definition, Therapeutic Patient Education (TPE) helps patients acquire or maintain the skills they need to manage their life with a chronic disease in the best possible way.

It is a basic, lasting component of patient management. It covers organised activities, including psychosocial support, designed to make patients fully aware about their disease and to inform them about care, hospital organisation and procedures, and health- and disease-related behaviours. It helps patients and their families understand and deal with the disease and its treatment together, in order to maintain or even improve quality of life.

The ERN-Skin conducted a survey among each ERN-Skin thematic group on Therapeutic Patient Education Programme and only a few of them adopted this holistic approach.

OBJECTIVES

- Identify available therapeutic patient education tools for each group of diseases
- Elaborate an ERN-Skin methodology for developing / accrediting these education programmes

1. THERAPEUTIC PATIENT EDUCATION TOOLS

The ERN-Skin thematic/disease groups and Skin ePAG worked together according to develop or endorse therapeutic patient education (TPE) tool.

- TPE tool endorsed by the ERN-Skin: each disease group assess the available TPE at the local and national level. When complying with standard TPE definition, the ERN-Skin board via each disease group endorses these tool.
- TPE tool elaborated with the participation an ERN-Skin member or several members : An ERN-Skin or several members contribute to the development of a new tool with other healthcare providers, European task forces or networks such as the European Academy of Dermatology and Venereology Task Force or the European Dermatology Forum
- TPE tool developed by an ERN-Skin or several members and then endorsed by the ERN-Skin thematic group: the tool is first developed at the national level. Then, the ERN-Skin disease group assess the tool and endorses it.
- TPE tool developed by the ERN-Skin. These tools follow the standard TPE tool definition

1.1. PATIENT BROCHURES

DEFINITION

ERN-Skin Patient Brochures provide information on the diseases, drugs, tips, for daily life.

ERN-SKIN PATIENT BROCHURES

- Epidermolysis Bullosa
 - Debra international – Epidermolysis Bullosa patient guides and infographics / recommended by the ERN-Skin
 - Available in English
- Ectodermal dysplasia
 - Everybody's Different / elaborated by the ERN-Skin
 - Available in English
 - A booklet for patient with ectodermal dysplasia: “JEDer ist anders” an healthcare teaching aid
 - Available in German

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- Autoimmune Bullous Diseases
 - Autoimmune Bullous Diseases VADEMECUM English / elaborated by the ERN-Skin
 - Available in English
 - Drugs used in Autoimmune bullous disease / elaborated by the ERN-Skin
 - Available in English
 - Information sheet for patients affected by Bullous Pemphigoid/ Written in collaboration with the Reference Centre for Autoimmune Bullous Diseases and the Pemphigus-Pemphigoïde France patient association and recommended by the ERN-Skin
 - Available in 2 languages: English and French
 - Information sheet for patients affected by Mucous Membrane Pemphigoids (cicatricial pemphigoid, epidermolysis bullosa acquisita, linear IgA dermatosis with mucosal involvement) /Written in collaboration with the Reference Centre for Autoimmune Bullous Diseases and the Pemphigus-Pemphigoïde France patient association and recommended by the ERN-Skin
 - Available in 2 languages: English and French
 - Information sheet for patients affected by Pemphigus /Written in collaboration with the Reference Centre for Autoimmune Bullous Diseases and the Pemphigus-Pemphigoïde France patient association and recommended by the ERN-Skin
 - Available in 2 languages: English and French
 - Information sheet for patients affected by pemphigoid gestationis Pemphigus /Written in collaboration with the Reference Centre for Autoimmune Bullous Diseases and the Pemphigus-Pemphigoïde France patient association and recommended by the ERN-Skin
 - Available in 2 languages: English and French
 - Tips for a salt-free and low sugar diet during general corticosteroid therapy/Written in collaboration with the Reference Centre for Autoimmune Bullous Diseases and the Pemphigus-Pemphigoïde France patient association and recommended by the ERN-Skin
 - Tips for the daily life of patients with an autoimmune bullous disease/Written in collaboration with the Reference Centre for Autoimmune Bullous Diseases and the Pemphigus-Pemphigoïde France patient association and recommended by the ERN-Skin
 - Available in 2 languages: English and French
 - Wound care guidelines – Local skin and mucosal care in pemphigus and pemphigoid / AutoImmune Blistering Diseases (AIBDs) This booklet is about the care needed by people with Pemphigus and Pemphigoid. It is the result of several years of exchanges, on the one hand, between the APPF and patients with autoimmune blistering diseases and their families; and, on the other, between the APPF and Professor Catherine Prost, dermatologist, co-coordinator of the National Expert Center for Blistering Toxic and Autoimmune Diseases / Recommended by the ERN-Skin
 - Available in 2 languages: English and French
- Xeroderma Pigmentosum
 - Patient pathway / Elaborated by the ERN-Skin
 - Available in English
- Ichthyoses
 - Guidelines for patients / Elaborated by the ERN-Skin
 - Available in English
- Cutaneous Mosaic Disorders Nevi & Nevoid Skin Disorders and Complex Vascular Malformations and Vascular Tumors
 - Frequently Asked Questions on Mosaicism / Elaborated by the ERN-Skin

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- Available in English
- Parent Support Guide – Caring for a Child with a Rare Condition 0-4 years / Elaborated by the ERN-Skin
 - Available in 7 languages: English, Dutch, French, Deutsch, Italian, Portuguese, Spanish
- Parent Support Guide – Caring for a Child with a Rare Condition 5-11years / Elaborated by the ERN-Skin
 - Available in 7 languages: English, Dutch, French, Deutsch, Italian, Portuguese, Spanish
- Parent Support Guide – Caring for a Child with a Rare Condition 12-17 years / Elaborated by the ERN-Skin
 - Available in 7 languages: English, Dutch, French, Deutsch, Italian, Portuguese, Spanish
- Severe Cutaneous Drug Reactions
 - SJS / TEN Patient Information Leaflet
 - Available in English

These ERN-Skin Patient Brochures are available on the ERN-Skin website.

1.2. TUTORIALS

DEFINITION

ERN-Skin tutorials are educational clips on rare conditions. These tutorials are developed by ERN-Skin partners for a specific condition and a specific care. Once produced by the ERN-Skin partner they are validated by the ERN-Skin thematic groups responsible for the specific condition

ERN-SKIN TUTORIALS

The ERN-Skin has developed educational tutorials on

- Learning about photoprotection for patients with albinism and xeroderma
 - Produced by FIMARAD, the French national network for rare dermatological diseases
 - Validated by the ERN-Skin Cutaneous Diseases Related to DNA Repair Disorders Thematic Group
 - Available in 2 languages: English, French.
- Hand mobility exercises for children suffering from epidermolysis bullosa in 2 languages: English, French
 - Produced by FIMARAD, the French national network for rare dermatological diseases
 - Validated by the ERN-Skin Inherited Epidermolysis Bullosa and skin fragility syndromes - Darier, Hailey-Hailey Thematic Group
 - Available in 2 languages: English, French
- Training on specific hand care for patients with epidermolysis bullosa in 2 languages: English, French
 - Produced by FIMARAD, the French national network for rare dermatological diseases
 - Validated by the ERN-Skin Inherited Epidermolysis Bullosa and skin fragility syndromes - Darier, Hailey-Hailey Thematic Group
 - Available in 2 languages: English, French
- Epidermolysis Bullosa and breastfeeding
 - Produced by the Ospedale pediatrico Bambino Gesù, Rome, Italy
 - Validated by the ERN-Skin Inherited Epidermolysis Bullosa and skin fragility syndromes - Darier, Hailey-Hailey Thematic Group
 - Available in 2 languages: English, Italian
- Epidermolysis Bullosa and oral hygiene

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- Produced by the Ospedale pediatrico Bambino Gesù, Rome, Italy
- Validated by the ERN-Skin Inherited Epidermolysis Bullosa and skin fragility syndromes - Darier, Hailey-Hailey Thematic Group
- Available in 2 languages: English, Italian
- Red Baby Movie

They are available on the ERN-Skin website.

2. HEALTHCARE PATHWAYS AND PATIENT JOURNEYS

2.1. UNDERSTAND THE HEALTHCARE PATHWAYS AND PATIENT JOURNEYS

The healthcare pathway is the patient's journey through the healthcare system. It refers to all the stages a patient experiences in the management of his or her disease, from pre-diagnosis to palliative care.

2.2. THE PATIENT JOURNEYS' DEFINITION AND METHODOLOGY

DEFINITION

Patient Journeys are visual testimonies that reflect the natural history/needs of patients and their families for a specific rare disease. They represent the collective perspective on the burden of the disease and the needs of people with first-hand experience of living with a rare skin disease.

It aims to :

- Engage the wider patient community to consolidate common needs for a specific rare disease
- Engage in a discussion with the clinicians to highlight the different (unmet) needs of a specific rare disease, both medical and psychological, so the clinicians can respond to these needs
- Keep in mind both the professional and patient are experts

METHODOLOGY

The patient journey methodology is

- Mapping the journey and identifying the needs and recommendations on ideal care for each specific skin disorder across the different stages from the first symptoms at birth to the end of life care
- Reviewing by both ePAG advocates and clinical experts (clinical presentation validated by some clinicians)
- Organising the information in easy reading graphics (table and illustration)
- Identifying the needs that are common for all 'skin disorders' (to be develop in the next steps)

2.3. THE ERN-SKIN PATIENT JOURNEYS

THE KEY ROLE OF THE SKIN ePAG

European Patient Advocacy Groups (ePAGs) bring together rare disease patient advocates who are actively involved in the work of the European Reference Networks. Each ePAG has a number of 'ePAG advocates', who represent their disease area in the ERN and the interests of the wider patient community.

The Skin ePAG is the ePAG advocate group of the ERN-Skin. Each member is a representative of a patient organisation. Within the ERN-Skin, ePag advocates are present in each thematic and transversal group and play a key role in governance.

The Skin ePAG have developed the patient journeys with the support of some thematic groups.

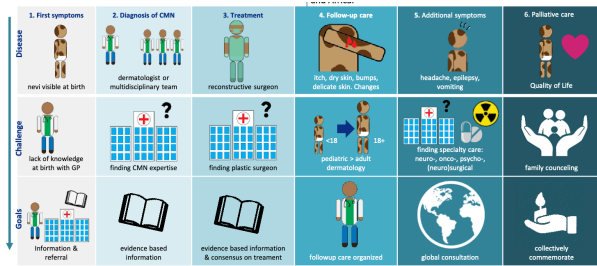
THE ERN-SKIN PATIENT JOURNEYS

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The Skin ePAG have developed the patient journeys with the support of some thematic groups:

- Congenital Melanocytic Naevus Syndrome
- Cutis Laxa with Arteries and Lung Symptoms
- Cutis Laxa with Neuro and Skeleton Symptoms
- Cutis Marmorata Teleangiectatica Congenita
- Ectodermal Dysplasia
- Netherton Syndrome
- Pemphigus Vulgaris



They are available on the ERN-Skin website.

3. DISSEMINATION

3.1. OBJECTIVES

The dissemination objectives were

- to patient empowerment

3.2. TARGET GROUPS

The target groups were:

- Patient representatives
- Patients
- Healthcare professionals
- Academic Communities and Scientific Societies
- Public Health Authorities
- Other ERNs
- Other European and international networks
- European Commission

3.3. INFORMATION

The following information was shared:

- Patient brochure
- Tutorials
- Patient journeys

3.4. ACTIVITIES

The ERN-Skin coordination and Skin ePAG shared information via:

- Website
- Newsletter
- Posters
- Presentation in congress and conferences
- E-Mailings
- Printing and distribution of emergency cards to each ERN-Skin member dealing with the diseases

4. NEXT STEPS

4.1. ADAPT AND MAKE AVAILABLE TPE TOOLS

The next step is to adapt to the national environment and translate in the national language the available TPE tools. ERN-Skin healthcare providers and Skin ePAG have started to translate these documents.

4.2. DEVELOP FULL TPE PROGRAMME FOR EACH CONDITION

The next step is to develop TPE programme for each condition covered by the ERN-Skin.

ABBREVIATIONS

- ERN-Skin: European Reference Network for Rare, Low Prevalence and Undiagnosed Skin Disorders
- TPE: Therapeutic Patient Education



<https://ec.europa.eu/health>



<https://ern-skin.eu>

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