



Webinars Cutaneous Lymphoma

EuroBloodNet  Topic on Focus

Patients' Organizations

How to connect patients in Europe to CL experts via the ERN

Prof Martine Bagot

ERN-EuroBloodNet Member

AP-HP Hôpital Saint Louis

ERN-EuroBloodNet subnetwork LYMPH

City Paris– Country France

26 April 2021

Pierre Aumont

ERN-EuroBloodNet ePAG

Association de Soutien et d'Information à la Leucémie Lymphoïde

Chronique et la maladie de Waldenström

ERN-EuroBloodNet subnetwork LYMPH

City Paris – Country France

26 April 2021

**LYMPHOMA
COALITION** 

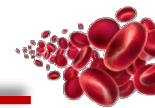
 **CUTANEOUS
LYMPHOMA
FOUNDATION**



 **EURORDIS**
RARE DISEASES EUROPE

 **European
Reference
Network**
for rare or low prevalence
complex diseases
Network
Hematological
Diseases (ERN EuroBloodNet)

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European Reference Networks

Due to the small number of patients for each rare disease, and the often limited knowledge, rare diseases, affecting less than 1 in 2000 individuals, is an area of public health in which joint efforts among EU Member States are justified and crucial.

European Reference Networks (ERNs) are virtual networks, involving specialised healthcare providers across Europe. They aim to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment, concentrated knowledge and resources.

ERNs are thematically based. Each ERN covers a broad group of rare diseases under its thematic network. On 1st March 2017, 24 ERNs were officially launched, involving more than 900 highly-specialised healthcare units from over 300 hospitals in 25 EU countries plus Norway. Since then, the ERNs are continuing to grow. **EuroBloodNet** is the ERN for all rare haematological diseases.

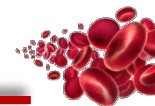


EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



What is ERN-EuroBloodNet?



60
Members

14
Members
States



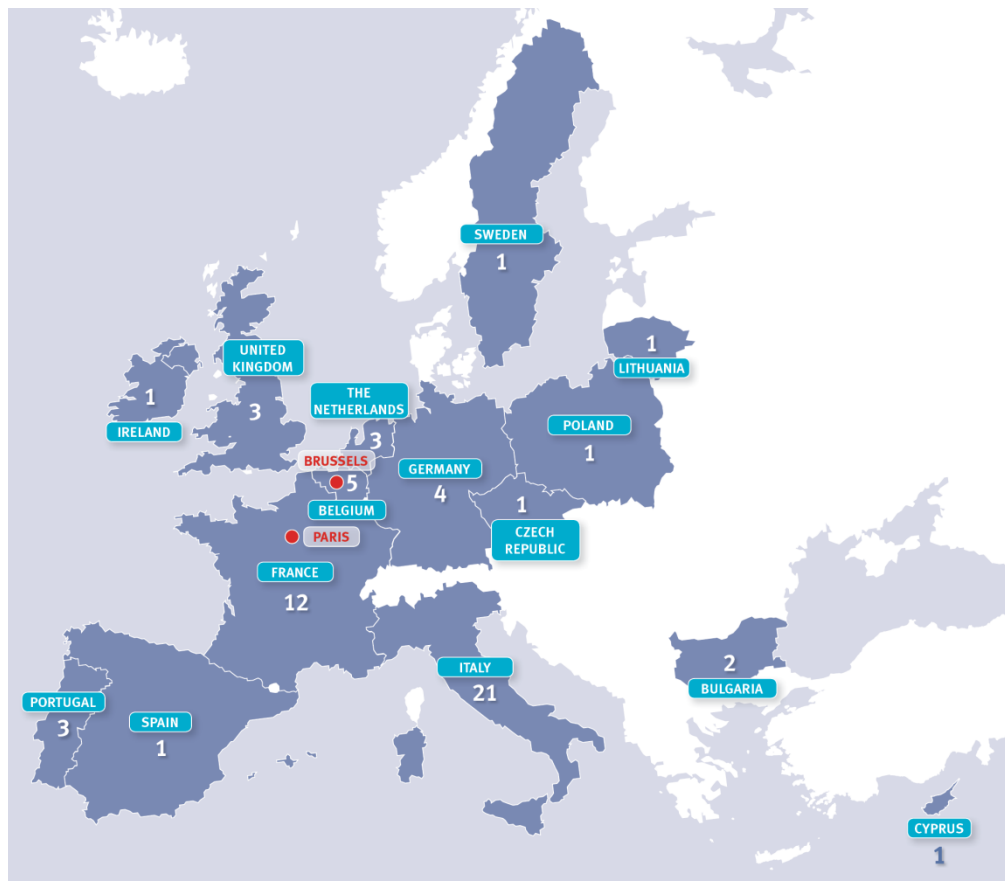
7 associated partner from 5 Member States

2 Austria
2 Denmark
1 Estonia
1 Hungary
1 Slovak Republic

3 national coordination centres in 3

Member States :

1 Malta
1 Slovenia
1 Luxembourg



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COALITION**

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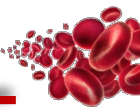


EURORDIS
RARE DISEASES EUROPE



**European
Reference
Network**
for rare or low prevalence
complex diseases

Network
Hematological
Diseases (ERN EuroBloodNet)



Oncological diseases Hub
Coordinated by Prof P. Fenaux
AP-HP, Hôpital St Louis, Paris

Non-oncological diseases Hub
Coordinated by Prof B. Gulbis
CUB-Hôpital Erasme – LHUB-ULB
Brussels

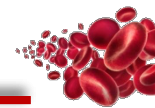
Myeloid malignancies
Lymphoid malignancies
Histiocytic disorders

Rare red blood cell defects
Bone marrow failures and rare haematopoietic disorders
Rare bleeding-coagulation disorders and related diseases
Haemochromatosis and rare iron metabolism disorders



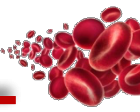
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Who are the ePAGs?

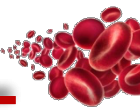


- In parallel to the establishment of 24 ERNs, EURORDIS has established **24 European Patient Advocacy Groups (ePAGs)** corresponding each to one 1 ERN:
 - Diseases covered in 1 ePAG = diseases covered in 1 ERN
- **ePAG Advocates** are nominated by their peers based on their advocacy track records to represent their patient community in a ERN
- ePAG Advocates are the **voice of patients in the ERNs and are involved in the Board, clinical domains and transversal task forces**



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Who are EuroBloodNet ePAGs?



Pierre Aumont

Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström



Baiba Ziemele

European Haemophilia Consortium (EHC)



Angelo Loris Brunetta

Thalassaemia International Federation



Sophie Wintrich

MDS UK Patient Support Group (and MDS Alliance)



Jan Geissler

Leukemia Patient Advocates Foundation



Maria Piggin

PNH Support



Ananda Plate

Myeloma Patients Europe



Dag Erling Stakvik

European Federation of Associations of Patients with Haemochromatosis (EFAPH)

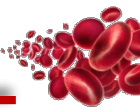


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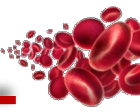
European Reference Network for rare or low prevalence complex diseases

Network Hematological Diseases (ERN EuroBloodNet)



What is EuroBloodNet doing for CL?

- Educational Online programs for health professionals and patients organizations
- E-learning Platform with videos and available accessible educational material for patients and health professionals
- Telemedicine (CPMS)
- Centralizing the access to cutting edge diagnostics tools and therapies above borders
- Collecting international guidelines
- Patients assistance for:
 - Searching expert health care provider
 - Cross Border Health

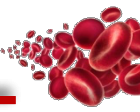


Let's see in details...



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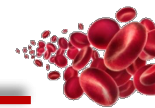


How to connect patients in Europe to CL experts via the ERN



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Cutaneous Lymphoma Network in France

- Groupe Français d'études des lymphomes cutanés (GFELC)

- Centers in France, Belgium and Switzerland

- Pathologic review of all cases

- Multidisciplinary meetings

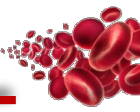
- Regional

- National

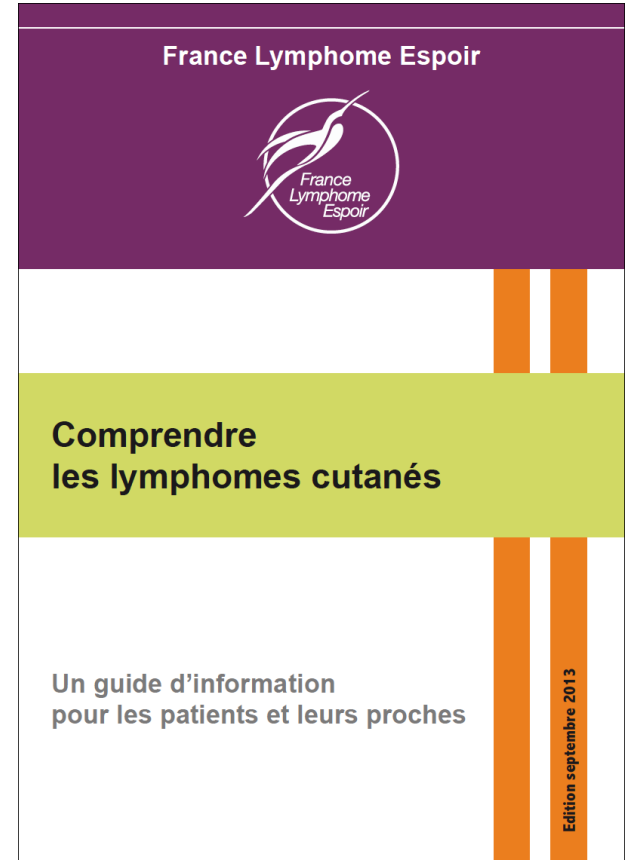
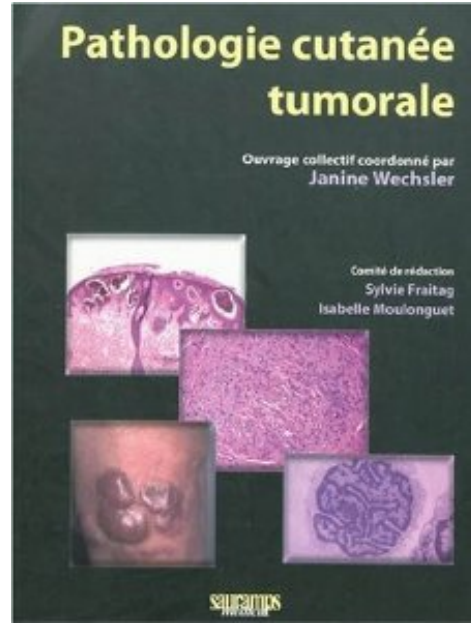
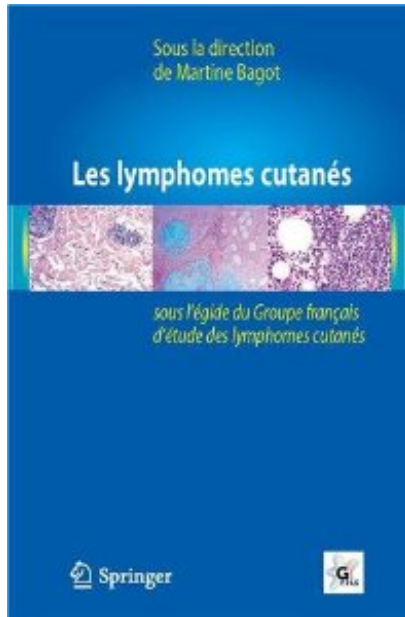
<https://gfelc.org>

- Clinical expert network labeled by INCa





Information for doctors and patients

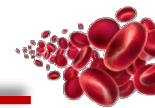


Close relations with France Lymphome Espoir



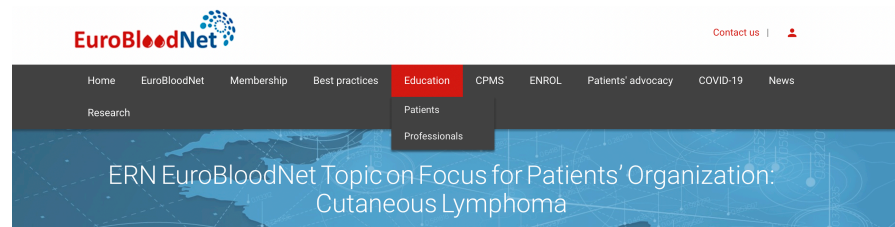
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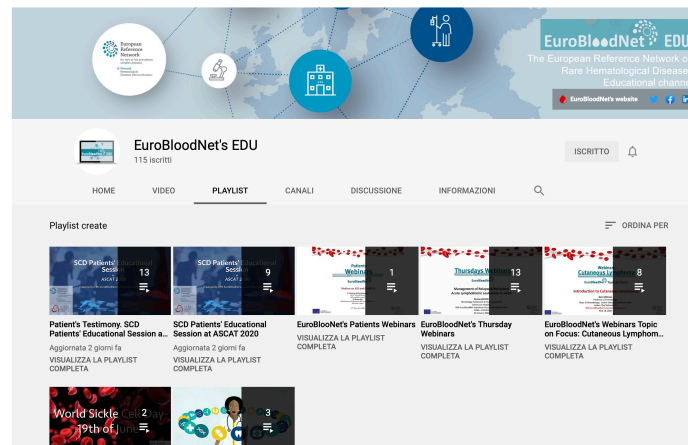


Information for doctors and patients

Repository of educational material: on EuroBloodNet website



Online educational video on EuroBloodNet's EDU YouTube Channel



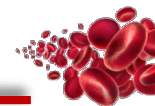
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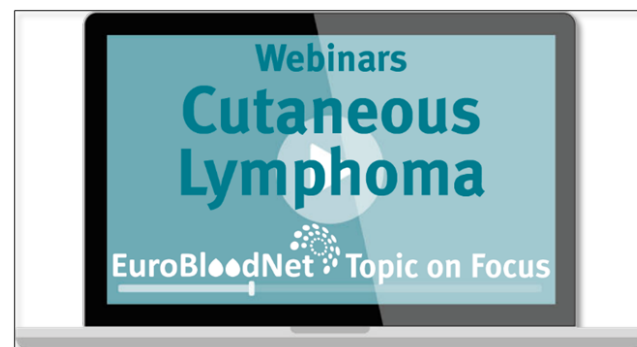
European Reference Network

for rare or low prevalence complex diseases

Network Hematological Diseases (ERN EuroBloodNet)

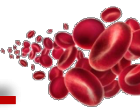


Webinar program on Cutaneous Lymphoma for Health Professionals



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You can watch all webinars on our YouTube channel EuroBloodNet's EDU!

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EuroBloodNet EDU
The European Reference Network on Rare Hematological Diseases

EuroBloodNet's website

Webinars
Cutaneous Lymphoma
EuroBloodNet Topic on Focus

Webinars
Cutaneous Lymphoma
EuroBloodNet Topic on Focus
Introduction to Cutaneous Lymphomas

PLAY ALL

EuroBloodNet's Webinars
Topic on Focus: Cutaneous Lymphoma (Health Professionals)

8 videos • 174 views • Updated today

Public

ERN-EuroBloodNet Topic on Focus: Cutaneous Lymphoma aims to disseminate very innovative topics among health professionals in order to give the visibility to the last cutting-edge advances in the field of Cutaneous Lymphoma. This objective responds not only to the need for in-depth knowledge sharing by international experts of this rare malignancy, but also to the need to create a repository of comprehensive educational material on all types of Cutaneous Lymphoma. In fact, there are several differentiations in Cutaneous Lymphoma sub-categories that require a specific educational knowledge from a clinical, pathological, etiological and phenotypic point of view. Webinars are provided by international experts in the field of Cutaneous Lymphoma and will be opened to every haematologist, paediatrician, or other health care professionals (EuroBloodNet members or not) interested in the topic.

SHOW MORE

EuroBloodNet's EDU

SORT

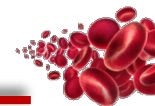
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - Introduction to CL
EuroBloodNet's EDU
WATCHED 44:17
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - Mycosis Fungoides
EuroBloodNet's EDU
WATCHED 46:35
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - Sézary Syndrome
EuroBloodNet's EDU
WATCHED 37:57
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - CD30-Hymphoproliferations
EuroBloodNet's EDU
WATCHED 37:15
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - Aggressive T-cell lymphomas
EuroBloodNet's EDU
WATCHED 1:04:58
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - PCFCL & PCMZL
EuroBloodNet's EDU
WATCHED 1:01:48
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - PCLBCL-LT
EuroBloodNet's EDU
WATCHED 55:11
- EuroBloodNet's Topic on focus: Cutaneous Lymphoma - New therapeutic developments I & II
EuroBloodNet's EDU
08:10

8 sessions of the accredited with 7 CME points, comprehensive webinar program for health professionals 'Topic on Focus: CL' is available on EuroBloodNet's EDU YouTube channel



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Date of the webinar	Topic	Speaker	link to the EuroBloodNet's website section
18th of May	Introduction to CL	Rein Willemze	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/1/introduction-to-cutaneous-lymphoma
8th of June	Mycosis Fungoides	Maarten Vermeer	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/2/mycosis-fungoides
6th of July	Sézary Syndrome	Martine Bagot & Pietro Quaglino	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/3/sezary-syndrome
14th of September	CD30+ lymphoproliferations	Werner Kempf	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/4/cd30-lymphoproliferations
28th of September	Aggressive T-cell lymphomas	Evangelia Papadavid & Pietro Quaglino	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/5/aggressive-t-cell-lymphomas
26th of October	PCFCL and PCMZL	Pablo Ortiz-Romero & Emmanuella Guenova	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/6/primary-cutaneous-follicle-center-lymphoma-pcfcl-and-primary-cutaneous-marginal-zone-lymphoma-pcmzl
16th of November	PCLBCL, Leg type	Marie Beylot Barry & Anne Pham-Ledard	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/7/primary-cutaneous-large-b-cell-lymphoma-leg-type-pclbcl-lt
14th of December	New therapeutic developments I & II	Julia Scarisbrick	http://eurobloodnet.eu/education/topic-on-focus-webinars/cutaneous-lymphoma/8/new-therapeutic-developments-i-and-ii



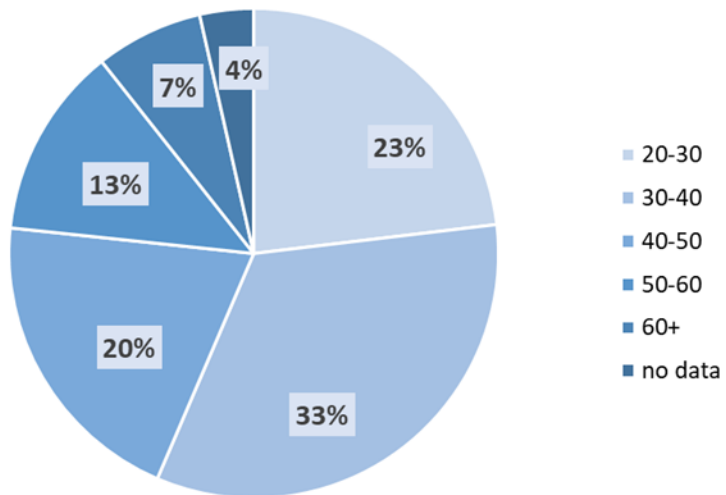
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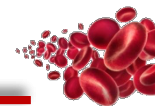
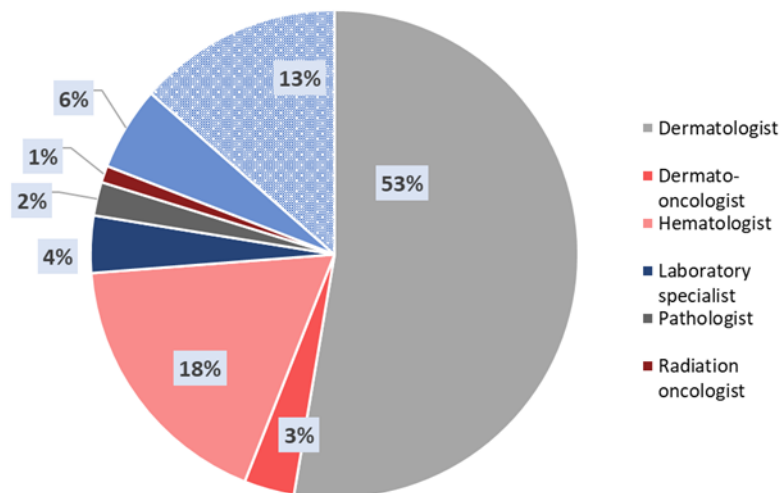
European Reference Network
for rare or low prevalence complex diseases

Network Hematological Diseases (ERN EuroBloodNet)

Age range of participants of Topic on Focus: CL webinar program



Professional role of participants of Topic on Focus: CL webinar program



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FOUNDATION**

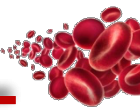


EURORDIS
RARE DISEASES EUROPE

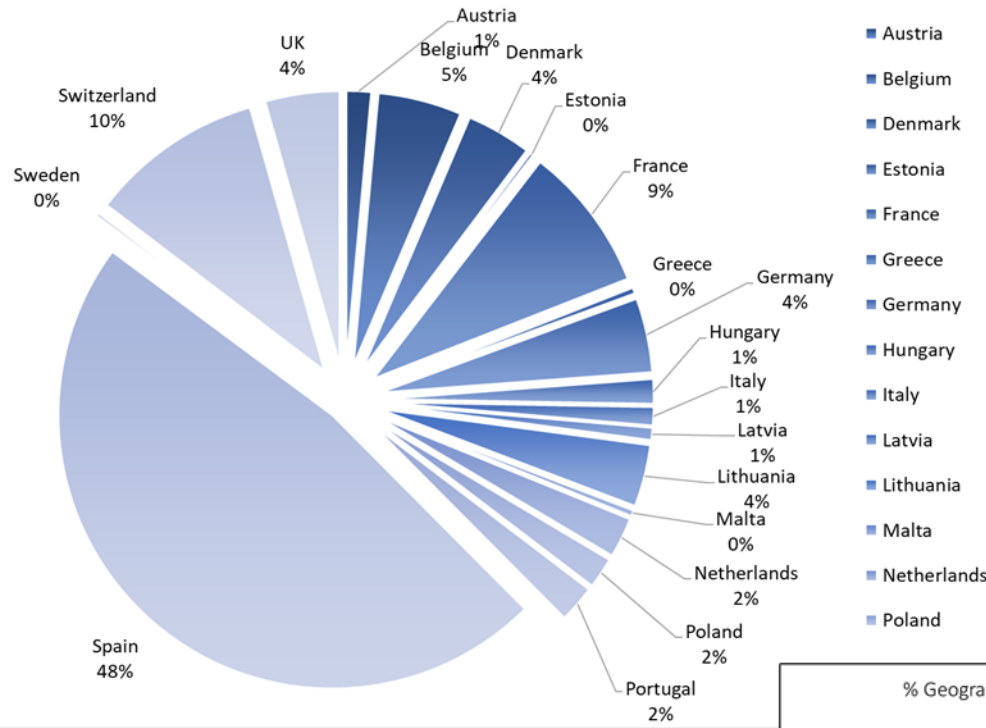


**European
Reference
Network**
for rare or low prevalence
complex diseases

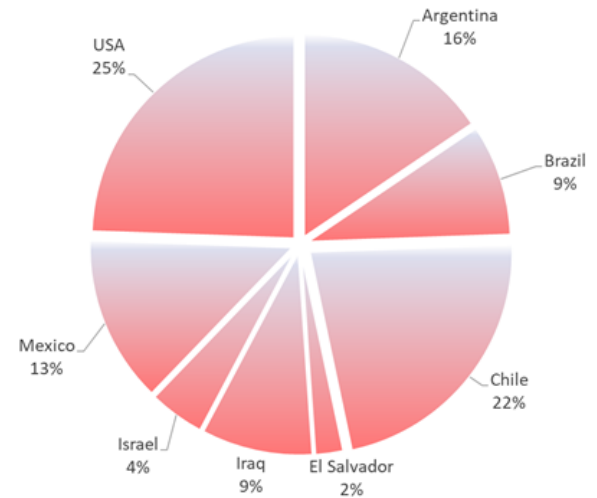
Network
Hematological
Diseases (ERN EuroBloodNet)



% Geographical distribution among participants in Topic on Focus: CL per session

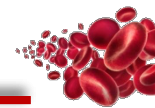


% Geographical distribution of participants in Topic on Focus: CL - among countries outside Europe



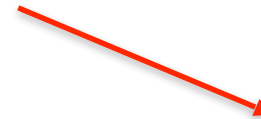
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Contact us for assistance (on the website):

- Searching expert health care provider
- Cross Border Health



Contact us | 



Home EuroBloodNet Membership Best practices Education CPMS ENROL Patients' advocacy COVID-19 News

Research

COVID-19

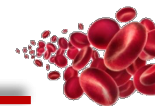
COVID-19 and Red Blood Cell Diseases

Join the ERN-EuroBloodNet Collaborative Platform on Red Blood Cell and COVID-19 to share clinical information for supporting daily medical practice and allow interprofessional consultations

 COLLABORATIVE PLATFORM



Expert physicians and patients organizations covering CL collaborating with the ERN



<https://eurobloodnet.eu/task-forces/cutaneous-lymphoma/cutaneous-lymphoma/>

Home EuroBloodNet Membership **Task Forces** Best practices Education CPMS ENROL Patients' advocacy
COVID-19 News Research

Cutaneous Lymphoma Task Force

Cutaneous Lymphoma Task Force



ERN-EuroBloodNet Task Force on Cutaneous lymphoma is formed by

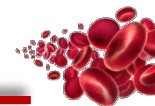
- **Virtual Board experts:** Health professionals belonging to:
 - ERN-EuroBloodNet members



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Searching for an expert physician:



Search experts

Search experts:

By disease

Type one disease *

PRIMARY CUTANEOUS LYMPHOMA 

By subnetwork

Subnetworks

OR 

- Bleeding - Coagulation disorders Bone marrow failure Haemochromatosis and other iron disorders
 Histiocytic Disorders Lymphoid malignancies Myeloid malignancies Red blood cell defects

Additional filters



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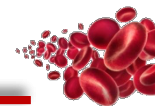


European
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 Network
Hematological
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Searching for an expert physician:



<https://eurobloodnet.eu/members/expert/search>

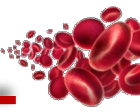


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European Reference Network
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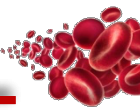


Clinical Patients Management System Cutaneous Lymphoma



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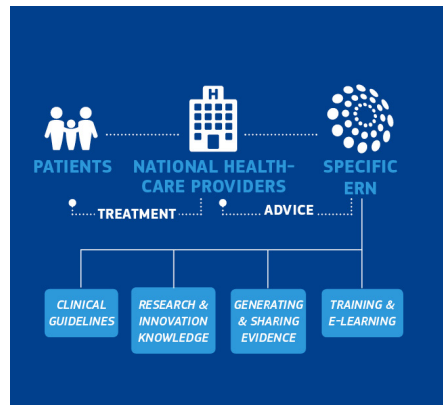




EuroBloodNet's CL Virtual Board of experts

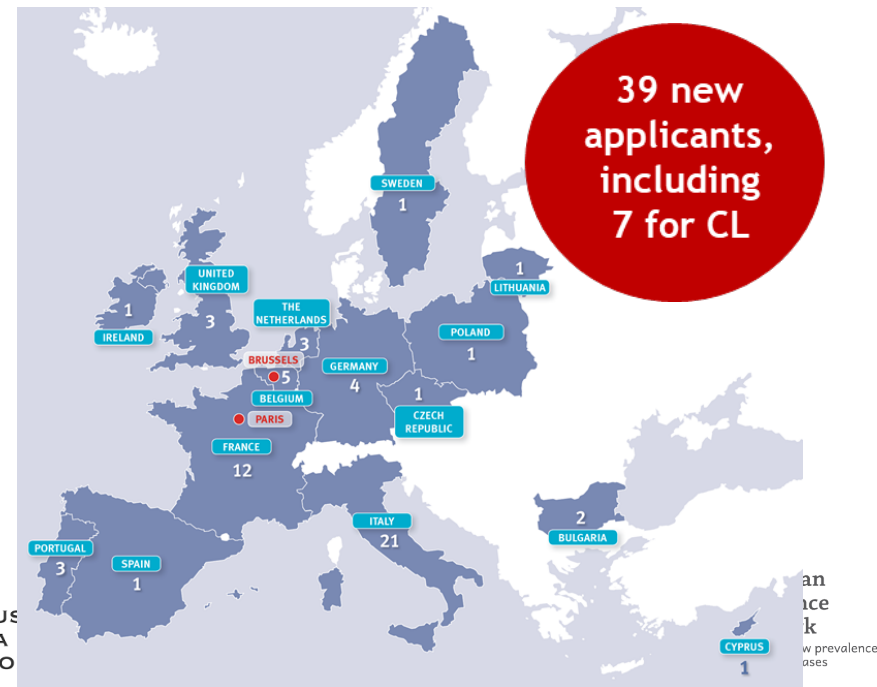
Established to provide expertise in different identified and agreed initiatives, to cover the needs due to the ultra rare prevalence using the facilities provided by ERN:

- educational programs for health professionals and patients,
- telemedicine (CPMS),
- centralizing the access to cutting edge diagnostics tools and therapies above borders,
- developing international guidelines



EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

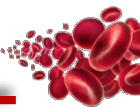
Share. Care. Cure.



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LYMPHOMA COALITION

CUTANEOUS LYMPHOMA FOUNDATION



Cutaneous lymphomas

Characteristics:

- Group of rare cancers
- Differ greatly in prognosis and therefore therapeutic approach
- Expert diagnostics and therapeutic advice is critically important for patient care

Challenge

- Knowledge is only available in specialized centers

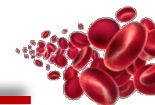
To address this medical need two initiatives have been developed

- Webinars
- CL Virtual Board in CPMS



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CL Virtual Board in CPMS – model development

Objectives:

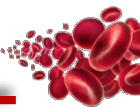
1. To recruit and train a board of experts in Cutaneous lymphoma registered in CPMS
2. To establish regular CPMS video meetings to consult cases on CL: diagnosis, treatment and follow-up.
3. To develop logistics for timely outcome report delivered to the patient



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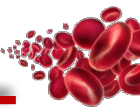


1. To recruit and train a board of experts in Cutaneous lymphoma registered in CPMS

EuroBloodNet's CL Virtual Board – 18 Experts

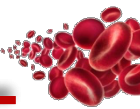
- 3 hematologists, 1 hematopathologist, 11 dermatologists, 7 dermatopathologists, 3 dermatooncologists and 3 oncologists
- 8 specialists from EuroBloodNet's Member Healthcare Centers, 2 from EuroBloodNet's Affiliated Center and 8 from Collaborating Centers.

Selection of EORTC CLWG members based on number of patients per center and access to advanced medical tools.



Board of experts in Cutaneous lymphoma

Name of the expert	Member	Affiliated Partner	Supporting Partner	HPC	Country	Initiative
Prof. dr Julia Scarisbrick		yes		University Hospital of Birmingham	UK	Webinar, CPMS
Prof. dr Marie Beylot-Barry			yes	CHU de Bordeaux-Hôpital Saint André INSERM U1053	FRANCE	Webinar, CPMS
Dr. Ulrike Wehkamp			yes	Klinik für Dermatologie, Venerologie und Allergologie Universitätsklinikum Schleswig-Holstein, Campus Kiel	GERMANY	CPMS
Prof. dr Maarten Vermeer	yes			Department of Dermatology, LUMC	NETHERLANDS	Webinar, CPMS
Prof. Emmanuella Guenova			yes	Dept. of Dermatology University Hospital CHUV, Lausanne	SWITZERLAND	Webinar
Prof. dr Pablo Ortiz-Romero			yes	Jefe de Servicio de Dermatología Hospital Universitario 12 de Octubre, Facultad de Medicina Universidad Complutense Madrid	SPAIN	Webinar, CPMS
Prof. dr Rudolf Stadler			yes	University Clinic for Dermatology, University of Bochum	GERMANY	Webinar, CPMS
Prof. dr Martine Bagot	yes			Dermatology Department INSERM U976, Hôpital Saint Louis	FRANCE	Webinar, CPMS
Prof. dr Pietro Quaglino			yes	University of Torino	ITALY	Webinar, CPMS
Prof. dr Robert Knobler		yes		Department of dermatology, Vienna	AUSTRIA	CPMS
Prof. dr Werner Kempf			yes	Dept. Dermatology, University Hospital Zürich;	SWITZERLAND	Webinar
Dr. Adèle De Masson	yes			Assistance Publique-Hôpitaux de Paris Hôpital Saint-Louis	FRANCE	CPMS
Dr Anna Dabrowska-Iwanicka	yes	yes		Department of Lymphoid Malignancies, Maria Skłodowska-Curie National Research Institute of Oncology	POLAND	CPMS
Prof. dr Margarida Lima	yes			Centro Hospitalar Universitário do Porto, Porto, Portugal	PORTUGAL	CPMS
PD dr Christina Mitteldorf			yes	University Medical Center Göttingen, Department of Dermatology, Venerology and Allergology	GERMANY	CPMS
Prof. dr J Hendrik Veelken	yes			Department of Hematology, LUMC	NETHERLANDS	CPMS
Dr Joanna Romejko-Jarosinska	yes	yes		Department of Lymphoid Malignancies, Maria Skłodowska-Curie National Research Institute of Oncology	POLAND	CPMS



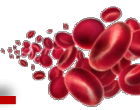
2. To establish regular CPMS video meetings to consult cases on CL: diagnosis, treatment and follow-up. Establishing a model for the efficient organization of VB CPMS meetings:

- Training of experts in CPMS
- Define a structure for regular meetings
- Develop the management of the meetings at the clinical and technical level



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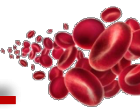
3. To develop logistics for timely outcome report delivered to the patient

- Develop logistic that the conclusion of the meeting is recorded in an outcome report
- Outcome report is shared with the referring physician.



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Results for objective 2 and 3:

Training

- Online CPMS workshops provided by EuroBloodNet resulting in:
 - 15 Experts registered and trained in CPMS
 - 2 residents/assistants managing patients' enrollment at HCPs

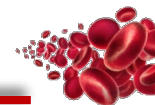
Structure

- Defined roles:
 - Medical Moderator: Prof. Maarten Vermeer
 - Secretary of the meetings: Dr. Ulrike Wehkamp
- Regular Schedule:
 - Once per month every First Wednesday of the month (17.00 – 18.00)
- Defined route and timeline for generation of outcome reports:
 - Summary of the meetings written in the chat also available in CPMS for Cutaneous Lymphoma Virtual Board experts
 - Generation of the outcome report within 2 weeks by Medical Moderator



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Experts actively participating in the CPMS meetings

Name of the expert	Member	Affiliated Partner	Supporting Partner	HCP	Country
Dr. Ulrike Wehkamp			yes	Klinik für Dermatologie, Venerologie und Allergologie Universitätsklinikum Schleswig-Holstein, Campus Kiel	GERMANY
Prof. dr Maarten Vermeer	yes			Department of Dermatology, LUMC	NETHERLANDS
Prof. dr Pablo Ortiz-Romero			yes	Jefe de Servicio de Dermatología Hospital Universitario 12 de Octubre, Facultad de Medicina, Universidad Complutense Madrid	SPAIN
Prof. dr Rudolf Stadler			yes	University Clinic for Dermatology Johannes Wesling Medical Centre, UK RUB, University of Bochum	GERMANY
Prof. dr Martine Bagot	yes			Dermatology Department INSERM U976, Hôpital Saint Louis	FRANCE
Prof. dr Robert Knobler		yes		Department of dermatology Medical University of Vienna	AUSTRIA
Dr. Adèle De Masson	yes			Assistance Publique-Hôpitaux de Paris Hôpital Saint-Louis	FRANCE
Prof. dr Margarida Lima	yes			Multidisciplinary OutClinic for Cutaneous Lymphoma and Mastocytosis, Centro Hospitalar Universitário do Porto, Porto, Portugal	PORTUGAL
PD dr Christina Mitteldorf			yes	University Medical Center Göttingen, Department of Dermatology, Venerology and Allergology	GERMANY
Prof. dr J Hendrik Veelken	yes			Department of Hematology, LUMC	NETHERLANDS

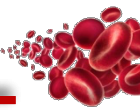


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European Reference Network
for rare or low prevalence complex diseases

Network Hematological Diseases (ERN EuroBloodNet)



Challenges and meetings strategy improvements

- Simplified features of CPMS platform:
 - PowerPoint presentations
 - CPMS case consultation form
- Simplified logistics of outcome report
 - Reducing generation of the outcome report from 2 weeks to 2 days

Eurobloodnet – Rare lymphomas - Case consultation form

PATIENT IDENTIFIER

CPMS PANEL NUMBER: #

DIAGNOSIS, STAGE, ED, AGE, GENDER

xxx

TREATMENT (PREVIOUS/CURRENT)

• xxx

COMORBIDITIES, CONCOMITANT MEDICATION

xx

Meds: xxx

EXAMINATION RESULTS

- Skin:
- Blood:
- Other:

QUESTION FOR CASE DISCUSSION

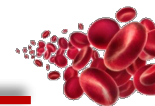
• Xx?

RESULT/CONCLUSION



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E O R T C
C L T F
2 0 - 2 1

M A R S E I L L E

Hémicycle de MPM
 Jardin du Pharo
 58, boulevard Charles Livon
 13007 – Marseille FRANCE

14-16 October
2021



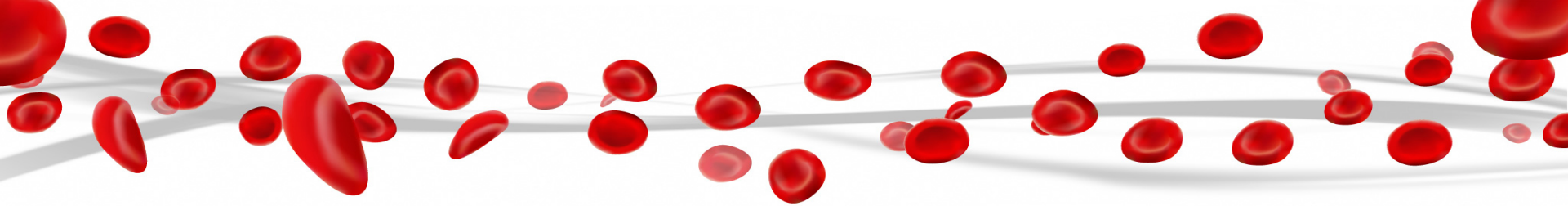
The future of cancer therapy



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Network
Hematological
Diseases (ERN EuroBloodNet)



Discussion

Please, write the questions in the chat

Webinars
Cutaneous Lymphoma

EuroBloodNet  Topic on Focus

Patients' Organizations