Best Practice
Cellulitis Flowchart for patients with lymphedema

Pediatric and Primary Lymphedema Working Group - VASCERN
Points to cover

• Introduction to VASCERN and Pediatric & Primary Lymphedema Working Group
• About lymphedema
• About cellulitis
• Flowchart
  • Idea generation
  • Method of work
  • Process
  • Dissemination
  • Next step
  • Summary
Meet us

Manuela Lourenço Marques
ePAG deputy Co-Chair for PPL and LINFA - Portugal

Pernille Henriksen
ePAG Co-Chair for PPL DALYFO - Denmark
Rare Multisystemic Vascular Diseases

48 expert teams from 39 highly specialized multidisciplinary Healthcare providers (HCPs) PLUS 6 Affiliated Partner Centers

Coming from 19 EU Member States

Over 70 Patient Organisations from all across Europe
VASCERN

- 6 working groups
  - PPL
  - MSA
  - HTAD
  - HHT
  - VASCA
  - Neurovascular - new
- 4 Transversal working groups
- HCPs
  - 20 countries covered incl. affiliated partners and UK
Pediatric and Primary Lymphedema

ePAG advocates and community

16 associations

14 countries

6 PPL ePAGs

Associação Nacional de Doentes Linfáticos (andLINFA) - Portugal
Association Vivre Mieux le Lymphoédème (AVML) - France
Bulgarian Association Lymphedema - Bulgaria
Dansk Lymfødem Forening (DALYFO) - Denmark
KIF11 Kids e.V. - Germany
Lega Italiana Lotta al Linfedema Aps - Italy
Lymphido OdV - Italy
Lymphoedeme Family - France
Lymphoedema Support Network (LSN) - UK
Lymph-what-oedema (LWO) - UK
Lymphoedema Ireland - Ireland
Nederlands Netwerk voor Lymfoedeem & Lipoedeem (NLNet) - The Netherlands
Norsk lymfødem- og lipødemforbund (NLLF) - Norway
Suomen lymfayhdistys - Finland
Svenska Ödemförbundet (SÖF) - Sweden
The Faroese Cancer Society - The Faroe Islands
Pediatric and Primary Lymphedema ePAG advocates

Pernille Henriksen
Dansk Lymfoedem Forening (DALYFO)
Co-chair

Manuela Lourenço Marques
Associação Nacional de Doentes Linfáticos (andLINFA)
Deputy co-chair

Eline Hoogstra
Nederlands Netwerk voor Lymfoedeem & Lipoedeem (NLNet)

Carina Mainka
KIF11 Kids e.V

Elena Matta
Lymphido Odv

Alain Pradel
Association Vivre Mieux le Lymphoédème (AVML)
Method of work and communication

- VASCERNdays & Face-2-Face meetings
- Monthly ePAG meeting
- Ad hoc ePAG meetings
- ePAG WhatsApp group
- Monthly RDWG meeting, ePAG co-chair and deputy co-chair
- Facebook group for advocates
- "Meet & Greet"
- Collaboration with sister patient associations
- Online meetings

PPL Working Group & ePAG

- Co-chair
- Co-chair WhatsApp group
- Monthly ePAG meetings hosted by EURORDIS
- ePAG meeting at VASCERNdays
- Transversal working groups
- Participation/organizing/speaking at conferences, training, webinars
- Collaboration with national societies, frameworks
- Participation in national ePAG networks
- Collaboration with other patient associations

VASCERN ePAG

Lymphedema Community

...beyond
About lymphedema

- Lymphedema is a **chronic** progressive disorder that occurs because the function of the lymphatic system is impaired.
- Lymphedema appears as a **persistent swelling** of the arms and/or legs in particular, but can also be present elsewhere on the body – one or more body parts or limbs can be affected.
- The disease is divided into primary and secondary lymphedema.
  - Primary lymphedema is a rare disease

St George’s classification algorithm of primary lymphatic anomalies
We are patients with lymphedema

Pascal w/ Milroys as a child @primarylymphedema

Leonor from Portugal

Mimi from France @mimi_lymphielife

Paul w/ KIF11 from Germany
Treatment

• There is no cure for lymphedema

• Treatment consists of daily management
  • skin care, compression, exercise, manual lymphatic drainage, keeping a healthy weight, for some a special diet is required

• surgery
What is cellulitis/erysipelas

- **Cellulitis** - a common, potentially serious bacterial skin infection.

- Children and adults with lymphatic impairment have a much higher risk of developing cellulitis/erysipelas.

- The clinical signs of erysipelas are: high fever (39-40°C) of sudden onset, with rigors, a ‘flu-like’ or unwell feeling, followed by redness, warmth, and increased volume of the affected limb.
Lymphoedema has been shown in several studies to be the strongest risk factor for cellulitis.

Al-Niaimi, 2009

Previous episodes of cellulitis are associated with a higher risk for recurrence.

Al-Niaimi, 2009

For primary lower limb lymphedema: male sex, greater body mass index, and younger age at lymphedema onset were associated with cellulitis.

Vignes S., 2022

A cross-sectional study (40 sites) in 9 countries. N=7477 (adults with uni- or bilateral chronic edema) 15-78% had cellulitis within the last 12 months.

Burian E., 2021

Lymphoedema has been shown in several studies to be the strongest risk factor for cellulitis.

Al-Niaimi, 2009
From the patients

- DALYFO – Denmark
  - 61% of those answering a poll (n=77) in a Facebook group who had not had cellulitis said they had **not been informed** by their primary doctor/therapists about the risks of cellulitis

- KIFTI – Germany
  - 13 parents with children up to 8 years
    - **Worried a lot about the risk of cellulitis**: n=10
    - Had been informed about the risk by their doctor: n=3
    - Found information online: n=10

- andLINFA – Portugal
  - 80% of those answering a poll (n = 29) said they were **afraid of getting cellulitis**

- Dutch patient journey
  - by ePAG Eline Hoogstra, n=35
  - 43% had experienced cellulitis
  - **29% had experienced cellulitis ≥ 10 times**
Collection of assets about cellulitis

- Pills of Knowledge
- Dos and Donts
  - Cellulitis
  - Skin Care
- Webinar
So what was missing?

- Something that combined all the most important information
- “Tangible” – bring in the handbag and for travelling
- Easy to read
- Addresses myths
- In local language
From a patient need to a flowchart

-**Groundwork**
-**Patient Need**
-**Patience & Time**
-**Discussions**
-**Creativity**
Process

Patient need
Understanding the patient need and scope of problem

Creation
Collection of information, draft(s), discussion, creation of format and layout

Validation
Validating the information and format, correcting and ensuring inclusivity

Translation
Translations and validations

Publication and Dissemination
Dissemination to patients and clinicians

Patient advocates

Clinicians

ERN coordination team
Collaboration Clinician – Patient to ensure.....

MEDICALLY CORRECT
EVIDENCE BASED
UP TO DATE
RELEVANT

INCLUSIVE
NEEDS BASED
PATIENT CENTERED
Considerations

- Layout
  - A4, 1-page
- ”Language”
- Short sentences, bulletpoints
- Translations
- Colours
- Pictogram
- Links and QR-codes
- VASCERN (ERN) look
Language availability

• **Currently available in**
  - English
  - French
  - German
  - Portuguese
  - Dutch
  - Danish
  - Swedish
  - Italian

• **Why do we need in so many languages?**
  - Inclusivity
  - Medical terms
  - Travelling
  - Safety
Dissimination – Social Media

- Facebook, Instagram, Twitter, LinkedIn
  - By VASCERN coordination team
  - Of patient associations and advocates

- Facebook groups
  - Questions about cellulitis

"Should I wear my compression when I have cellulitis?"

"Is this cellulitis?"

"Why do I keep getting cellulitis?"
Dissimination – everywhere else

- Added to websites of the patient associations
- Newsletters
- Email replies
- Present at webinars and conferences
- Hand out paper copies at patient workshops
- Encourage patients to give a copy to their GP
- Information in printed membership magazine
Next step

• Keep sharing with patients to raise awareness of both identification and prevention of cellulitis
• Review periodically
• More translations
  • Both western and eastern European languages are missing
• Part of our ongoing awareness campaign with clinicians on the risk and connection with lymphedema
Summary

• Listen to the patients – what are the needs
• Have the goal in mind while going through the process
• Keep working on it – have patience
• Ask for opinions, suggestions, corrections
• Ensure inclusivity
Thank you for joining us today