



Patient advocates working together

Marjolein van Kessel
September 11th 2019
Brussels

Agenda:

Introduction attendees

- What is patient advocacy?
 - What can we do?
 - How to organize?
- Workshop: patient journey
- Presentation Pedro
- Meeting Anne Fledderus
(OCOMEN)



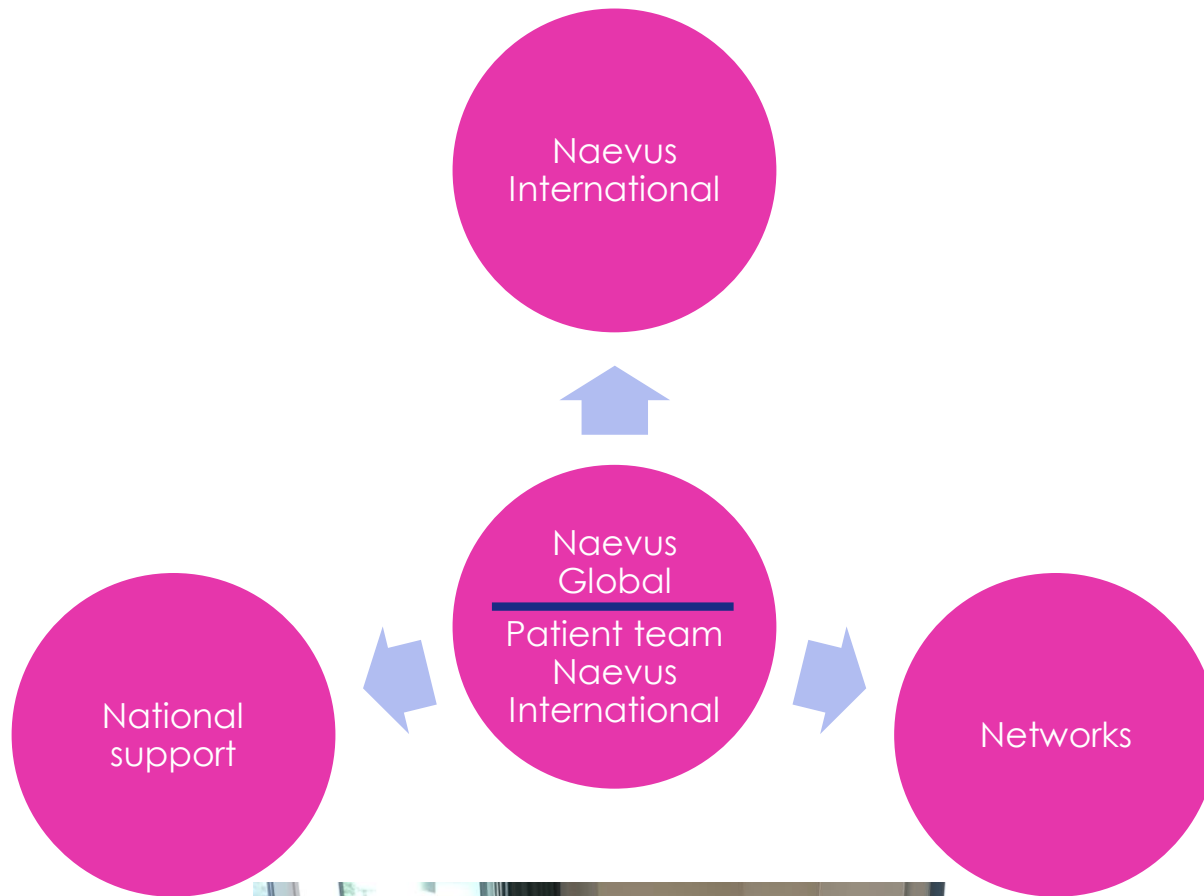
French meeting 2018 La Roche Posay

Patient advocacy is

1. Defending patient rights
2. Access to
 - healthcare
 - medicines
 - technologies
3. Patients and their families
 - Education / information
 - Support
4. Collaboration and sharing
5. Patient representation / building awareness
6. Education healthcare providers



Global Skin 2019



Naevus International 1st meeting 2018

1. Defending rights

2. Access to

- a) Healthcare
- b) Medicines
- c) Technologies

Learn

- Patients (national support)
- Naevus International
- Other networks

Defend

- Naevus International
- National support groups
- Use other networks

Naevus Global formalized

Chairman: Stefan Wilms

Treasurer: Janny Prooij

Secretary: Marjolein van Kessel

Board member: Ester Prooij

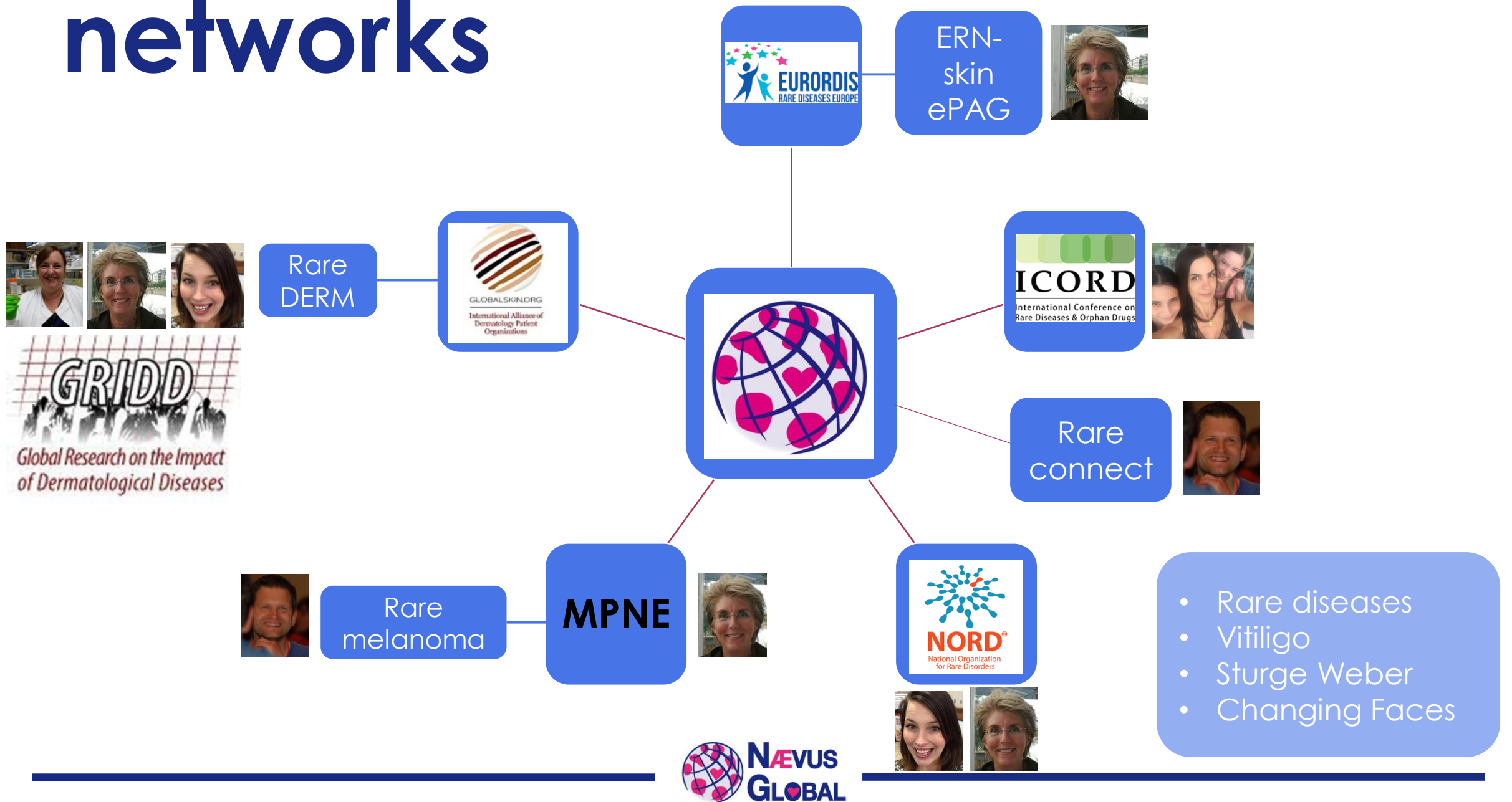


June 19th 2019

Why?

- Register to networks
- Independent from Naevus International
- Naevus Global umbrella for national CMN patient organizations
- Naevus International: non-registered network
researchers, clinicians, psychologists and patients

networks



Workplace





Launching soon . . . Rare Diseases International online community





- Eurordis
(anja.helm@eurordis.org)
- Global Skin
(shona.fleming@globalskin.org)
- RDI (Rare Diseases International)
(info@rarediseasesint.org)






Home



Notifications



Chats



Marjolein


Search 


All Notifications 


 Susan Thornton commented on your post in RareDERM - Community. 3d


 Stevens Johnsons Syndrome Canada posted in RareDERM - Community. 1w

 Tammi Shipowick created a poll in Create RareDERM Hub & Registries (Working/Advisory... 1w


 Julius Muungano posted in Workplace by Facebook help. 1w


 Shona Fleming likes your post in RareDERM - Community: "Nice to be connected through ... 1w




 Stay informed by following Laurence Gallu and Olivia Mullins and other people you ... 1w


 Emanuele Regalini followed you. 2w





Invite Coworkers

 **RareDERM - Community**
Closed Group



About Posts Files More 

Write Post  Create Photo A...  Create Doc  More


 Write something...



 Add file  Add Photo/Vi...  Tag coworkers 


FROM NOTIFICATIONS

 **Marjolein van Kessel**
August 15 at 4:05 PM ·  Add Topics


Nice to be connected through Worplace!
Thank you for adding me to this group.


 2 1 Comment Seen by 19




 Like  Comment

 **Susan Thornton** Hello Marjolein - lovely to "see you" 😊

Like · Reply · 3d · Edited

 Write a reply...
Press Enter to post.

 Write a comment...
Press Enter to post.

Search group...








About

Description



All members of our RareDERM community are welcome to share and collaborate here!



Members (93)



+ Find and add members


Suggested Members

 Bernd Arents 


 Melanie Funk 

 África Luca de Tena 

Invited

 christine@globalskin.org
[Send Reminder](#)

Shared In This Group

Chats 

2. Patients and their families

a) Education / information

b) Support

- Websites
 - Naevus International
 - National support groups
 - Naevus Global website, content?
- Conferences
 - Naevus International 1x / year
 - National meetings
- Social media 
 - Naevus Global
 - National social media
- NI communications team
 - Newsletter? Annual report?



Caring Matters Now London 2016

3. Collaboration and sharing

Communication between patient advocates

What to share:

- Good practices
- Information from Naevus International/conferences
- Information from networks

How:

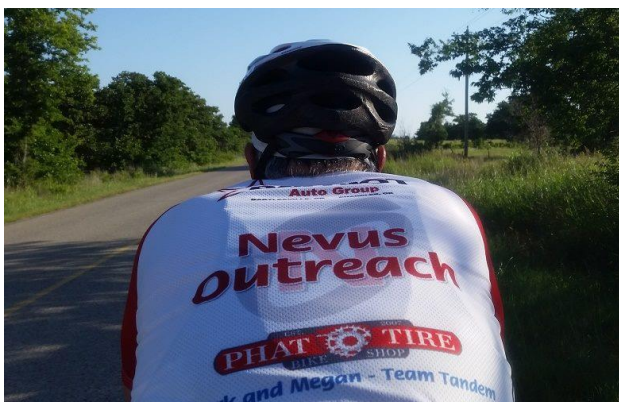
- Naevus Global meeting
- Facebook 'CMN patient advocate group'
- e-mail
- ?



German gathering 2018

4. Patient representation

a) Building awareness



8. Education of their healthcare providers

We need your input!

Patient Journey

- Timeline birth – entire life
- Visual approach for the clinical pathway of patients

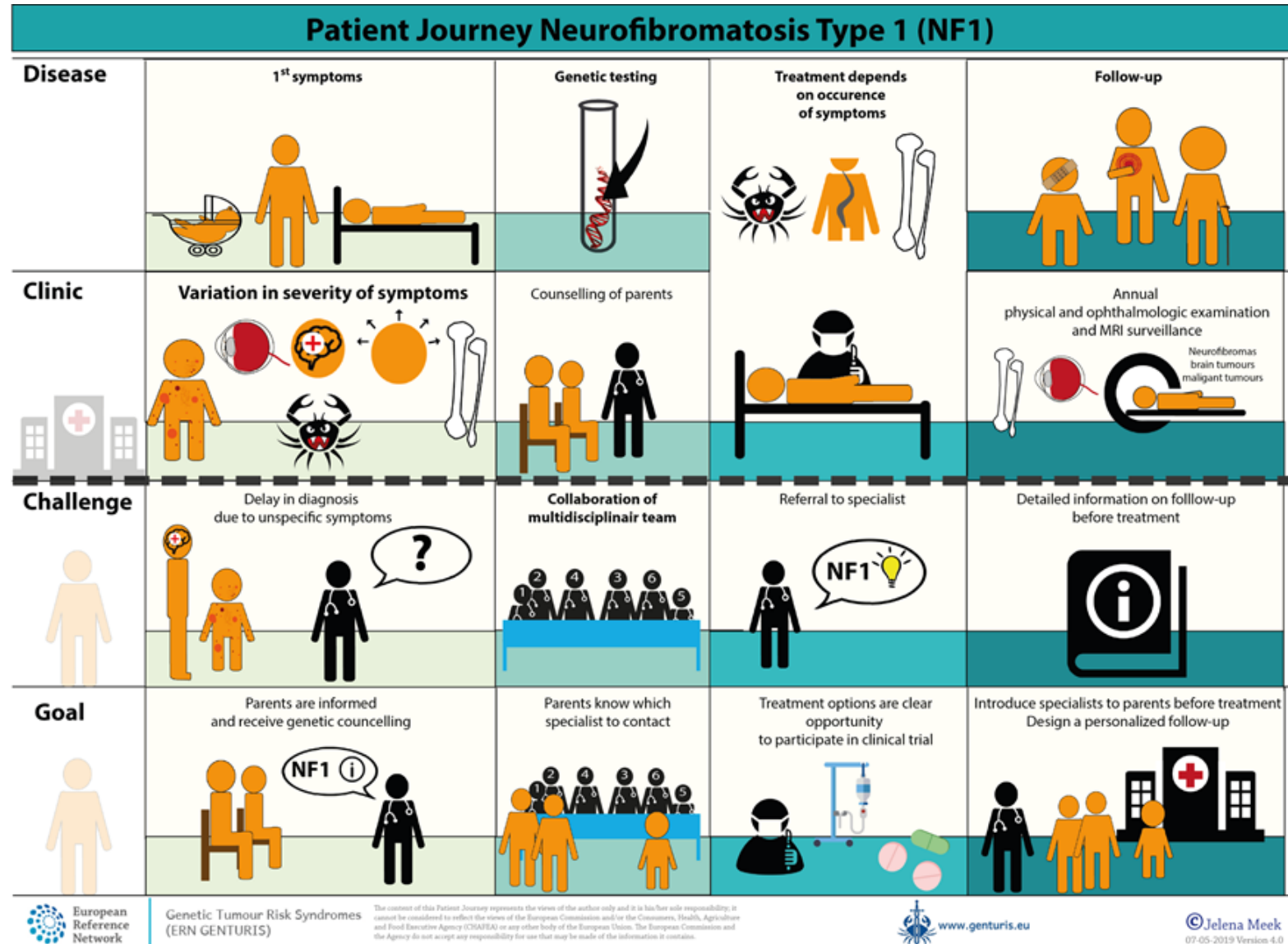
Each phase of the journey:

- Symptoms
- Diagnosis/treatment/clinicians
- What can be improved → challenges and needs
- Goals



Naevus International 2018

Example from Neurofibromatosis



Discussion

1. Our communication: Facebook or e-mail?
2. Naevus Global website. Ideas?
3. Naevus Global Facebook
4. Newsletter

Take home message

1. Share good practices
2. Visit conferences (Eurordis, NORD, etc.)
3. Meet at Naevus conferences
4. Naevus Global is for all of us



London 2016

Questions?



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marjoleinvankessel@gmail.com

Thank you

Dank u wel

Gracias

Danke

Merci

Diolch yn fawr

Спасибо

شكرا

谢谢

धन्यवाद

σας ευχαριστώ

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terima kasih

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köszönöm

நன்றி