



Working together for CMN



How can we improve the lives of
those affected by CMN/NCM
on a world wide level?

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1.1 Introduction Marjolein



1998



2010



2012

1. Lack of (correct) information
2. More than just a skin problem
3. No understanding
4. Feeling of not being taken seriously
5. Poor healthcare
6. Unnecessary hospitalizations
7. Unnecessary testing
8. >10 years diagnosis NCM

1.2 Living with a rare disease

In addition to essential daily tasks, people living with a rare disease and carers have to deal with the coordination of care



1.3 The patient

The patient of today is:

- Overloaded with health information
- Lacking support to understand our choices
- Challenging healthcare professionals with new information/questions
- Unaware of how new healthcare technologies are/ will impact our health
- Not involved in the development of healthcare's future

The patient of tomorrow is:

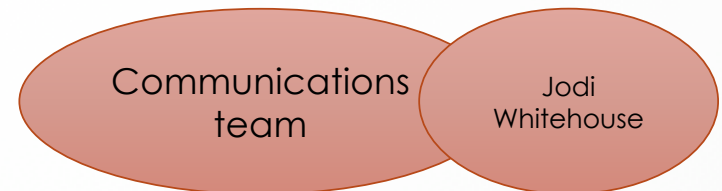
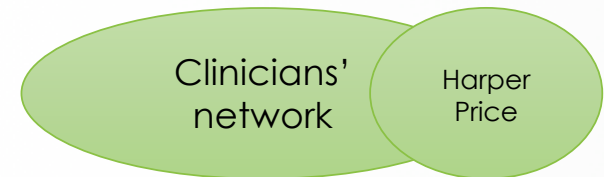
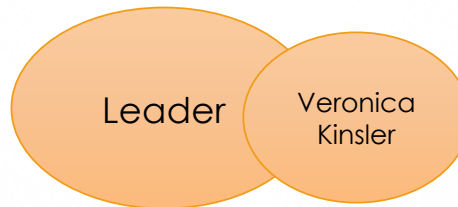
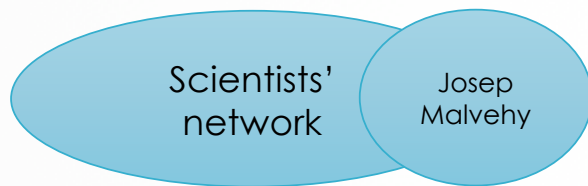
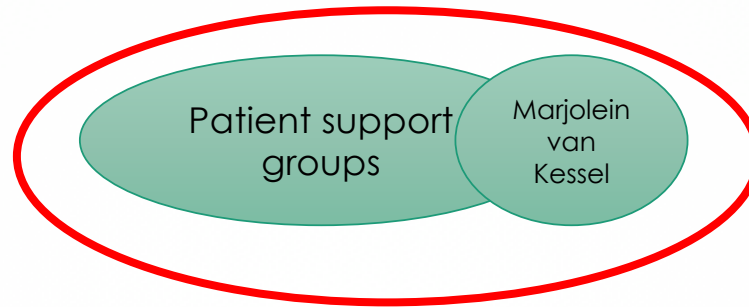
- Connected (self-monitoring)
- Better informed (social media + online diagnosis)
- More engaged in our healthcare decisions
- Owns and manages their medical information

2. History international activities CMN

- 2011 Tübingen
- Naevus Global 2013 Expert meeting
- Naevus International 2017



2. History international activities CMN



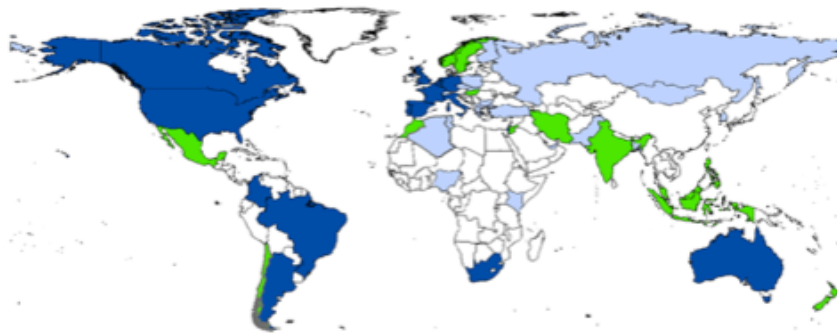
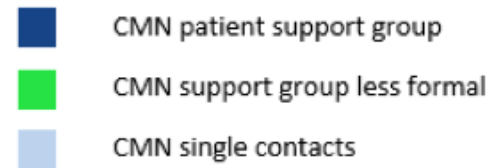
3.1 Awareness



- Multi lingual website: Naevus International
- Facebook page
- Newsletters
- Awareness at conference (Patient village)
- Share information and experiences from support groups
- Visiting other support groups
- Sign up at www.naevusinternational.com

3.2 Support

- How to assist affected children in countries without structured medical care?
- Connecting new countries (Focus Marjolein)
- Visiting other support groups
- Facebook
- NI Psychosocio team



3.3 Research

- Collaboration
 - OCOMEN (PROMs, the Netherlands)
- Registration, biobank
- Sharing information for patients
 - Naevus International Conference
 - Readable scientific articles and summaries



MPNE

- Other networks: Eurordis, Global Skin, Melanoma Patient Network Europe, NORD, ICORD

AIM OF THE PROJECT OCOMEN

To develop an international consensus on the important outcomes to measure, the so called Core Outcome Set (COS), before, during and after treatment for patients with Congenital Melanocytic Naevi (CMN).

The results can be used to:

- Harmonize outcomes reported in CMN studies
- Enable comparison of treatments' effectiveness
- Set up treatment guidelines for CMN

3.4 Advocacy

Working together

- Solidarity and support
- Listen to other's opinions
- Respect
- Equity and professionalism

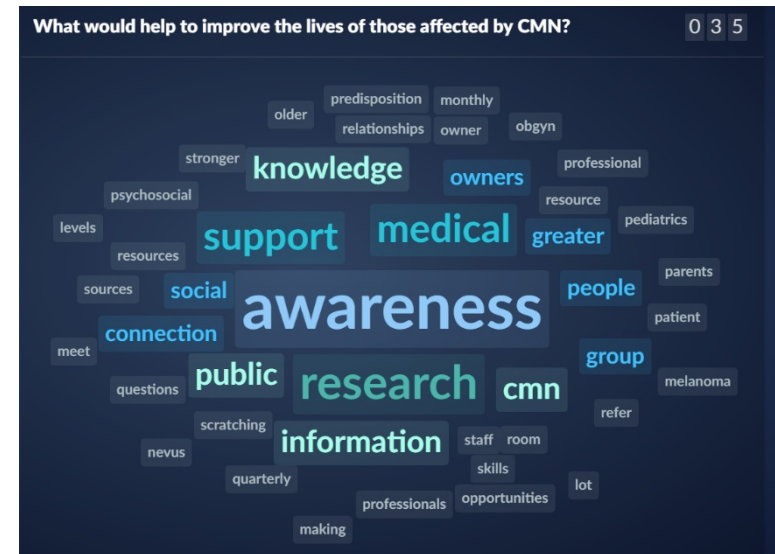
Expert meeting

- Open for patient advocates
- The patient team giving presentations to researchers and clinicians
- Patients are the experts!



4. Results Nevus Outreach conference

- Awareness (10)
 - Awareness for medical professional- especially OBGYN, pediatrics, and their supporting staff.
- Research (12)
- Information (10)
 - Also have a resource that summarizes those who are experts on the condition that they can consult or refer to.
- Support (13)
- Fundraising (1)



5. Take home message

Importance of working together worldwide:

- Awareness of our rare disease
- Inform patients, clinicians
- Support patients worldwide
- Collaboration in research
- Reach out to other networks



Thank you!

Dank u wel

Gracias

Danke

Merci

Diolch yn fawr

Спасибо

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谢谢

धन्यवाद

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