



How Naevus International can help patient groups

Marjolein van Kessel

Patient team leader

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Introduction



Dafnis 1998-2012

diagnosis
symptomatic NCM
not diagnosed for 13
years



Marjolein van Kessel
The Netherlands
Team leader Patients

Patient Advocate
2019 e-PAG Eurordis
2016 MPNE
2013 Naevus Global

Dutch guidelines:

- CMN
- Pediatric melanoma
- Palliative care

Agenda

- Birth
- Diagnosis
- Treatment removal
- Neurological problems and melanoma
- Daily life
- Palliative care
- Achieved
- Conclusion



Birth



What is the reason behind this type of giant nevus? Is it due to eclipses during pregnancy?



India

In my 35 years as a doctor, I've never seen anything like this.



Gynaecologist USA

I was in Tanzania for half a year. I saw a few patients with CMN. Besides control and resection of suspicious lesions, not much could be done.



Dermatologist trainer
Tanzania/Malawi

Birth

Diagnosis

Treatment
removal

NCM/
Melanoma

Daily life

Palliative care

Diagnosis

I have consulted three doctors from Delhi and Mumbai. Everyone has a different opinion and method. So we are quite confused by now.



India

MRI results showed "98% was clear". They did not use contrast and therefore could not say 100%. I am thinking about pushing through for another MRI to be done with contrast.



Norway

Our neurologist gave some very scary statics: 50% chance it will turn to melanoma, which is fatal. Unknown but likely possibility of fine motor skill and/or cognitive deficits. After the jaw-dropping 30 minute appointment we left.



USA

Birth

Diagnosis

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removal

NCM/
Melanoma

Daily life

Palliative care

Needs at birth & diagnosis

- Information
- Map of CMN/NCM experts → CMN/NCM expert 🧑🏻🧑🏻
- Patient/peer support in country
- Research and registration
- Psychological support
- Identify needs



Birth

Diagnosis

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Melanoma

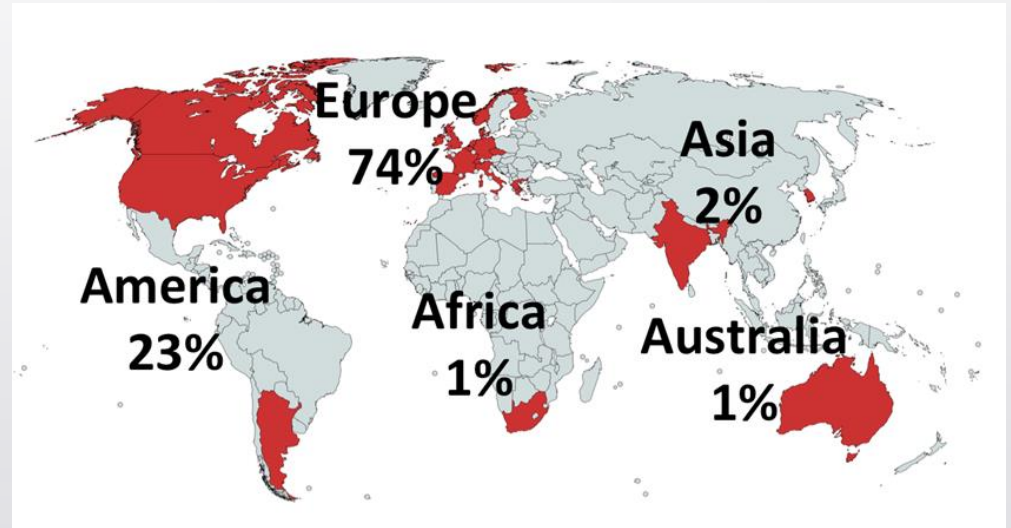
Daily life

Palliative care

OCOMEN

Participants who rated the importance of outcome domains

- 52 Patients and 29 Parents
- 63 Professionals



Birth

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Core outcome set for CMN

| CLINICAL CARE SETTING | RESEARCH SETTING |
|-----------------------------|-----------------------------|
| Quality of life | Quality of life |
| Malignancy | Malignancy |
| Neurological manifestations | Neurological manifestations |
| Anatomy of the skin | Anatomy of the skin |
| Complications | Pathological analysis |



Birth

Diagnosis

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removal

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Treatment removal

His incision had 100 stitches in his back and neck. It did not remain closed. He was discharged, and we drove the 2.5 hours home. The next day his wound appeared abnormal and I drove him all the way back.

USA



We considered all options here in Colombia, South America, but we didn't find the best option here. Now we're talking with Dr Bauer in Chicago USA

Columbia



I am Egyptian, living and working in Qatar. I tried my best here in Qatar but lack professional expertise. I am writing to seek any possible help as I do not have the financial resources to seek treatment internationally.

Egypt



Birth

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Daily life

Palliative care

Needs in removal treatment

- Information
- Map of experienced plastic surgeons
- Patient/peer support
- Psychological support
 - during/after treatment
 - family members
- Finances surgery/cross boarder healthcare
- Research and registration
- Identify needs →



Birth

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Neurological symptoms/melanoma

My daughter's legs are different. I saw the right leg has no power like the left leg. Is it because of the birthmark? I live in Korea . I didn't find an expert . I don't see other children like my daughter



South Korea

The doctors in Indonesia are generally reluctant to correspond with overseas doctors



Indonesia

This medical journey has become an expense that is hard on us and an emotionally taxing journey. I was working full time prior to my son's seizures and on going medical needs. I'm beyond stressed out trying to care for him and navigate resources.



USA

Birth

Diagnosis

Treatment
removal

NCM/
Melanoma

Daily life

Palliative care

Needs with NCM/Melanoma

- Information
- Map CMN/NCM experts → CMN/NCM expert 🐶🐶
- Local patient/peer support
- Psychological support
 - during/after treatment
 - family members
- Research and registration
- Identify needs



MPNE



Birth

Diagnosis

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NCM/
Melanoma

Daily life

Palliative care

Daily life

Has anyone else dealt with being accused of abuse because their kids Nevus looks like a bruise?



USA

While he was getting his haircut two guys started laughing at him hysterically and said "that haircut won't help him with all those moles."



USA

Someone noticed my daughter's shirt was soaked with blood. She had no idea what tore her nevus skin this time. On the back she can't see it or bandage it herself... making her feel helpless and frustrated.



USA

Birth

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NCM/
Melanoma

Daily life

Palliative care

Needs in daily life

- Information
- Local dermatologist → CMN expert 🧑🏻‍⚕️ 🧑🏻‍⚕️
- National patient/peer support
- Psychological support → 
- Identify needs ↘



Birth

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Palliative care

Palliative care, terminal care and memorial

Do we stay and fight the unknown and try to give him more time. Should I swoop him up and take him to the places he wants to go, or do I ask for more treatments and hope that we still have that time.



USA

We had a port placed in my son and started immunotherapy on the same day. The port placement was probably the second worst surgery he had out of eight. It was painful and it took weeks for him to recover. It had to be placed on the opposite side because the shunt was placed on his right side. The infusion was long. Immunotherapy takes time to work and it takes planning. It should be used in conjunction with radiation to really make it effective quicker. This disease just does not give you that kind of time.



Birth

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Palliative care

Palliative care, terminal care, memorial

- Information
- Local medical team → CMN expert 🧸
- Patient/peer support
- Psychological support
- Research
- Identify needs

MPNE



Memorial at Nevus Outreach conference 2018

Naevus International

- Website with information in 8 languages, soon 15
- email contact with Naevus International experts
- Yearly conference to exchange knowledge in research
- Psychological strategy - organization Anna
- Awareness Photo exhibition Do you C me Now



Patient/peer support

18 national patient support group
16 less formal support groups
~20 individual contacts

Networks for

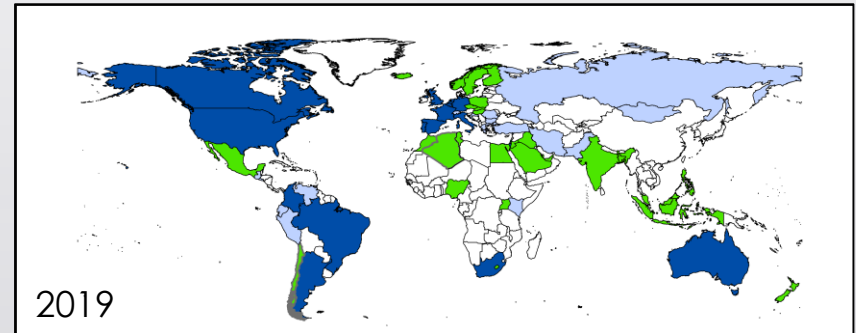
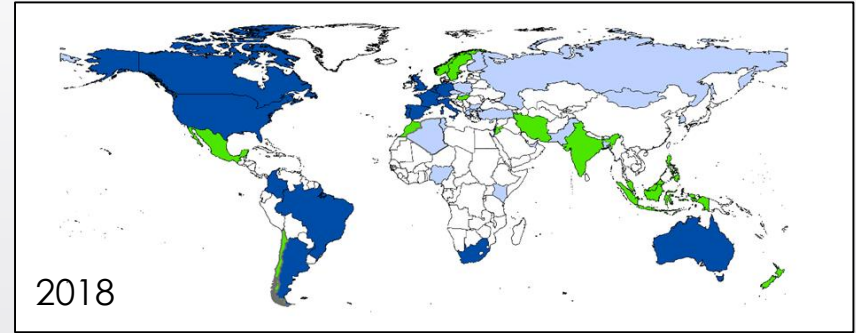
Africa

Nordic countries

Hispanic North America

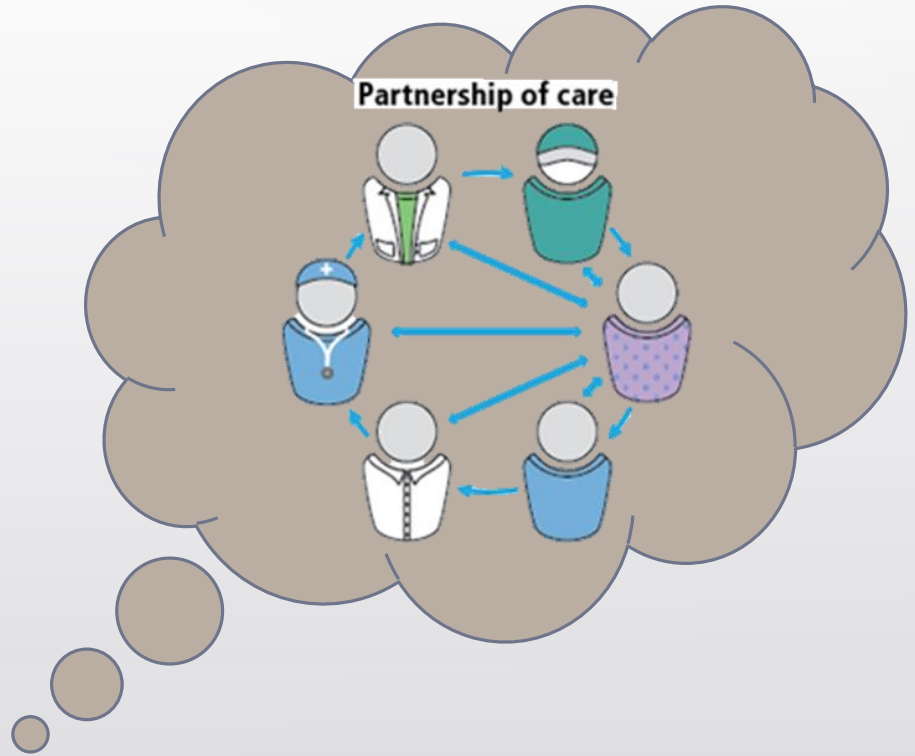
Arabic countries

Facebook groups for patient/peer
support melanoma, NCM, memorial

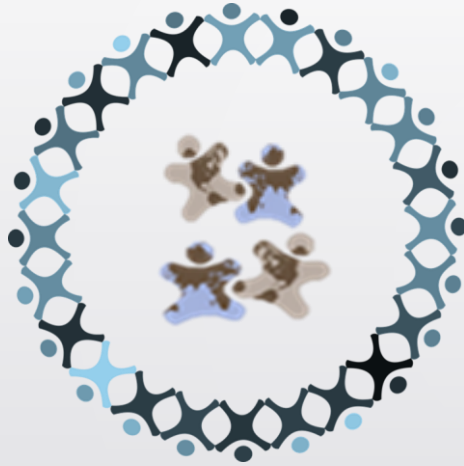


Challenges ahead

- Collaboration
- Psychological support
- Research and registration
- Easy access to information
- Patient journey to identify needs and set priorities



Questions?



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Thank you

Dank u wel

Gracias

Danke

Merci

Diolch yn fawr

Спасибо

شكرا

谢谢

धन्यवाद

σας ευχαριστώ

תודה

terima kasih

teşekkür ederim

köszönöm

நன்றி