Marjolein and Naevus Global 2017-2025

Presentation Naevus Global
Prague
April 22-23, 2025

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Introduction

Marjolein van Kessel
The Netherlands
Dafnis 1998-2012

birth

diagnosis

treatment
4 weeks old

living with CMN

13 years old
complications

Burn-out

What would have made life easier

- Fast and correct information at birth
- Information neurological symptoms
- Find experts
- Understand Dafnis’ behavior
- Understand Dafnis’ poor motor skills
- The impact on siblings
- The impact on my relationship
- Information palliative care

Marseille
2013

Presidents:

- Stefan Wilms (2013-2015?)
- Michelle Sibbons (2016-2017)
- Marjolein van Kessel (2017-2025)

Complicated:

- Prioritize work national organizations
- Organize in person meetings
- Bylaws and finances
- Personal issues

Nevus Netwerk Nederland

- Board not functioning

Feeling lost and alone

NO FINANCES (SOME REMAINING FUNDS)

NO OFFICIAL ORGANIZATION

WEBSITE

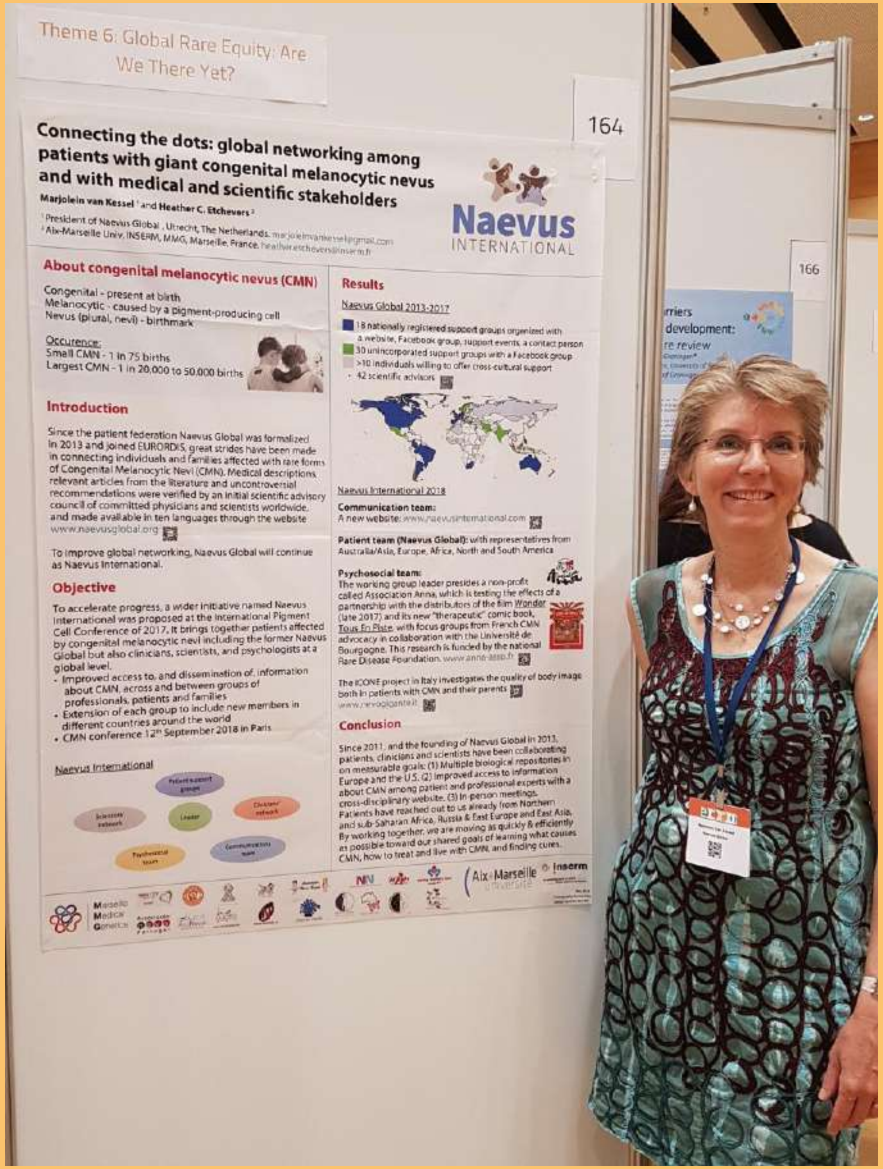
FACEBOOK PAGE

PRESENT POSTER AT EURORDIS

CONNECT WITH ORGANIZATIONS (EURORDIS, GLOBAL SKIN, MPNE, ETC.)

NAEVUS INTERNATIONAL VERSUS NAEVUS GLOBAL

SUPPORT FROM LEX!



Theme 6: Global Rare Equity: Are We There Yet?

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Connecting the dots: global networking among patients with giant congenital melanocytic nevus and with medical and scientific stakeholders

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Naevus INTERNATIONAL

About congenital melanocytic nevus (CMN)

Congenital - present at birth
Melanocytic - caused by a pigment-producing cell
Nevus (plural, nevi) - birthmark

Occurence:
Small CMN - 1 in 75 births
Largest CMN - 1 in 20,000 to 50,000 births

Introduction

Since the patient federation Naevus Global was formalized in 2013 and joined EURORDIS, great strides have been made in connecting individuals and families affected with rare forms of Congenital Melanocytic Nevi (CMN). Medical descriptions, relevant articles from the literature and uncontroversial recommendations were verified by an initial scientific advisory council of committed physicians and scientists worldwide, and made available in ten languages through the website www.naevusglobal.org

To improve global networking, Naevus Global will continue as Naevus International.

Objective

To accelerate progress, a wider initiative named Naevus International was proposed at the International Pigment Cell Conference of 2017. It brings together patients affected by congenital melanocytic nevi including the former Naevus Global but also clinicians, scientists, and psychologists at a global level.

- Improved access to, and dissemination of, information about CMN, across and between groups of professionals, patients and families
- Extension of each group to include new members in different countries around the world
- CMN conference 12th September 2018 in Paris

Naevus International

Results

Naevus Global 2013-2017

🟦 18 nationally registered support groups organized with a website, Facebook group, support events, a contact person
🟩 30 unincorporated support groups with a Facebook group
⬜ >10 individuals willing to offer cross-cultural support
- 42 scientific advisors

Naevus International 2018

Communication team:
A new website: www.naevusinternational.com

Patient team (Naevus Global): with representatives from Australia/Asia, Europe, Africa, North and South America

Psychosocial team:
The working group leader presides a non-profit called Association Anna, which is testing the effects of a partnership with the distributors of the film Wonder (late 2017) and its new "therapeutic" comic book, Tous En Piste, with focus groups from French CMN advocacy in collaboration with the Université de Bourgogne. This research is funded by the national Rare Disease Foundation. www.anna-asso.fr

The ICONE project in Italy investigates the quality of body image both in patients with CMN and their parents www.nevogigante.it

Conclusion

Since 2011, and the founding of Naevus Global in 2013, patients, clinicians and scientists have been collaborating on measurable goals: (1) Multiple biological repositories in Europe and the U.S. (2) Improved access to information about CMN among patient and professional experts with a cross-disciplinary website. (3) In-person meetings. Patients have reached out to us already from Northern and sub-Saharan Africa, Russia & East Europe and East Asia. By working together, we are moving as quickly & efficiently as possible toward our shared goals of learning what causes CMN, how to treat and live with CMN, and finding cures.

Marseille Medical Genetics

Aix-Marseille Université

Inserm

NÆVUS GLOBAL

Connections

- 2014…2024 **Nevus Outreach**
- 2017 **Nevus Italy**
- 2014 and 2016 **Caring Matters Now**
- 2018 and 2019 **Naevus International**
- 2018 **Naevus 2000** (la Roche Pose)
- 2018 **Eurordis**
- 2014, 2016, 2018, 2020 **Global Skin**
- 2018, 2019, 2024 **MPNE** and **MELCAYA**
- 2022, 2024 **WCRSD**
- 2023 **EADV**
- 2024 **PEDRA**

People:

Inbal, Heather, Benni, Mark, Jodi, Viola and Rosalba, Gaelle, Beatrice, Anne Fledderus, Julia Laibahas, Pedro Lopez, Cindi Colby

Experts

Veronica Kinsler, Suzanne Pasmans, Harper Price, Yasmin Khakoo, Carry Coughlin, Andrea Diociaiuti

Naevus Global updates

- Online meetings
- In person meetings with Naevus International 2018 and 2019
- OCOMEN research
- Nevus Outreach
- Guidelines CMN (the Netherlands)
- ERN-skin, ePAG member

Information

website

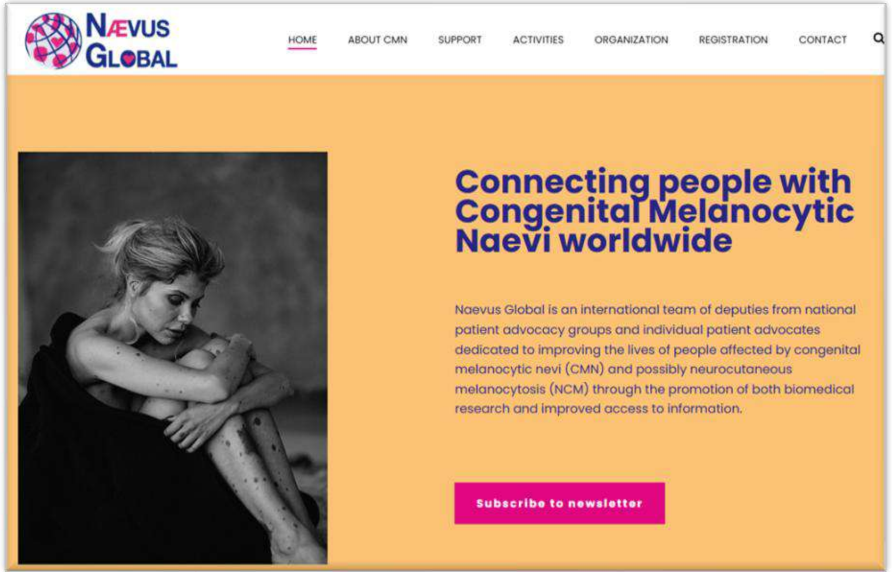
- 2018 take over and rebuild
- 2023 rebuild based on patient journey

Collecting and designing materials

- List of books (reading books, stories, picture books, etc.)
- Parent support guides (from Caring Matters Now), 6 languages
- Translation Tous en Piste, 6 languages, 5 printed
- Skin at School (not yet published)

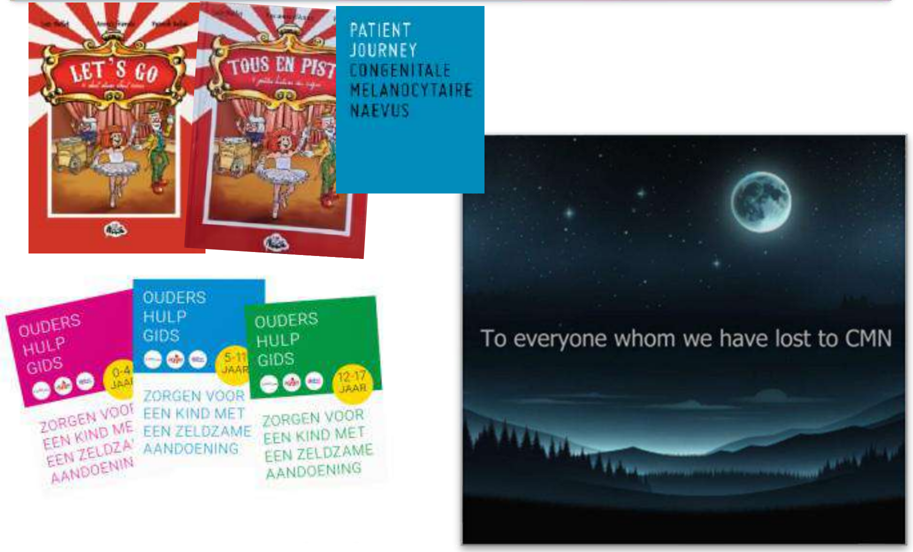
Support

- List CMN videos published on youtube
- Share impressive stories from Facebook (with permission)
- List social media channels
- Memorial videos (Quinten)



Connecting people with Congenital Melanocytic Naevi worldwide

Naevus Global is an international team of deputies from national patient advocacy groups and individual patient advocates dedicated to improving the lives of people affected by congenital melanocytic nevi (CMN) and possibly neurocutaneous melanocytosis (NCM) through the promotion of both biomedical research and improved access to information.



Collecting contacts worldwide

On website:

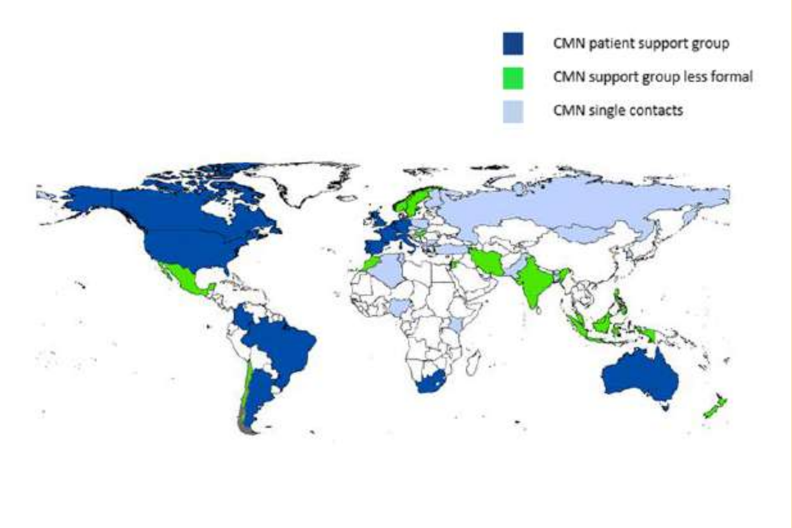
- CMN organizations
- Social media contact groups
- From original website: scientific advisory council

How:

- CMN organizations: 4/5 online meetings
- Search on Nevus Outreach facebook and connect

Not shared public:

- Individuel contacts
- List of scientific advisors contact details



2024 - 2025

‘Vier handen op een lege buik’

- Impact the loss of a child has in a relationship
- Learn impact on relation
- Deal with feelings of guilt

Change in life:

- 2 BnB’s and a workshop place
- Change in my paid work
- End of patient advocacy, Naevus Global and NNN

Questions?

Dank u wel
Gracias Danke
Merci
Diolch yn fawr
Спасибо
شكرا
谢谢 धन्यवाद
σας ευχαριστώ
תודה terima kasih
teşekkür ederim köszönöm
நன்றி

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