



Collaboration with patient representatives

Chord Cousin Collaboration Meeting
Amsterdam University Medical Hospital
September 24, 2024
Marjolein van Kessel

Introduction



Marjolein van Kessel
The Netherlands
Dafnis 1998-2012

diagnosis



birth



1

treatment
4 weeks old

2



3

4

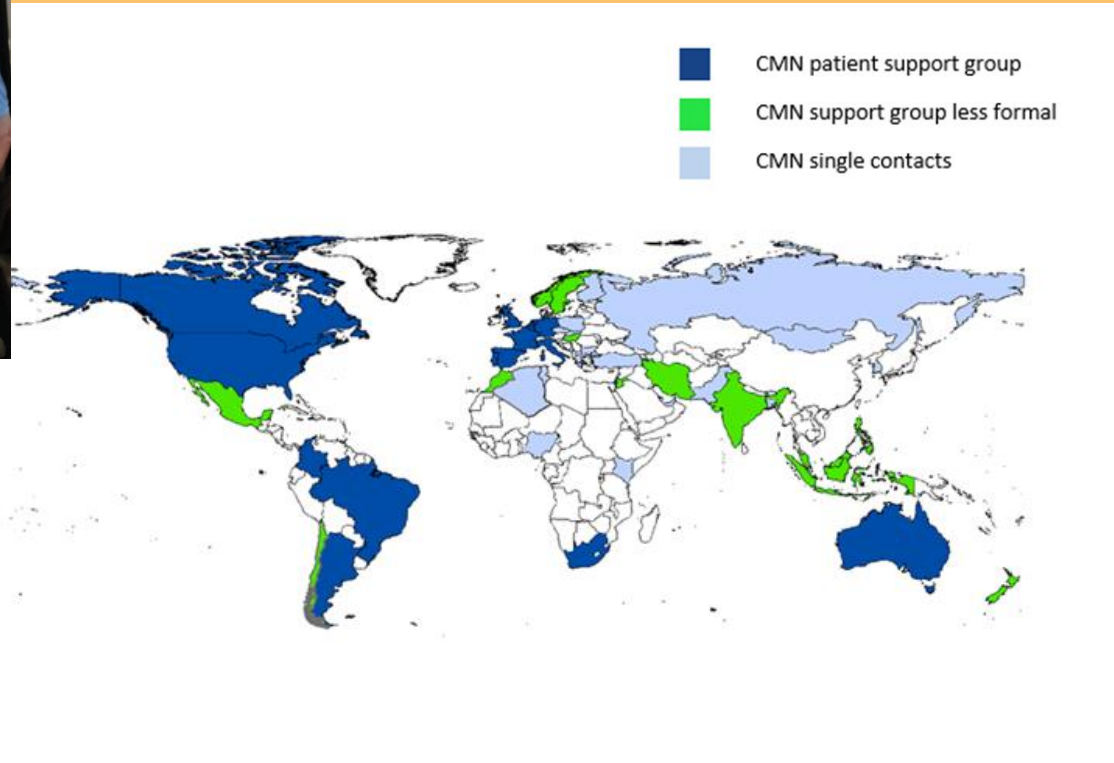


13 years old
complications



living with CMN

Naevus Global 2013-2024



OCOMEN



THE OUTCOMES FOR CONGENITAL MELANOCYTIC NAEVI (OCOMEN) PROJECT

WHAT IS THE PROBLEM?

At the moment, studies on Congenital Melanocytic Naevi (CMN) often measure different outcomes. Imagine two studies about treatment for CMN: Study A measures the color of CMN after treatment and Study B measures the number of complications.

When the two studies are finished, their results cannot be compared or combined, because different outcomes were used. This lack of uniformity makes it difficult to decide what the best management options are.

AIM OF THE PROJECT

To agree on a set of outcomes that should be measured in all research and clinical practice: the so-called CMN Core Outcome Set.

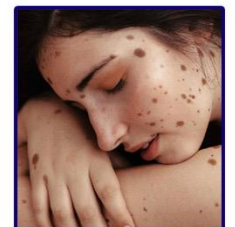
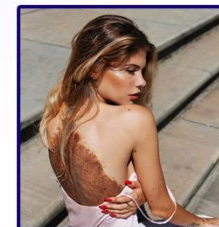
This Core Outcome Set will be developed with the help of people with CMN, their families and professionals.

HOW CAN YOU HELP US?

Let us know what outcomes are important for you by participating in different meetings or completing questionnaires.

If you are interested in participating, please e-mail Nevus Global or our OCOMEN research team.

Contact: a.c.fledderus@amsterdamumc.nl



Need for patient involvement



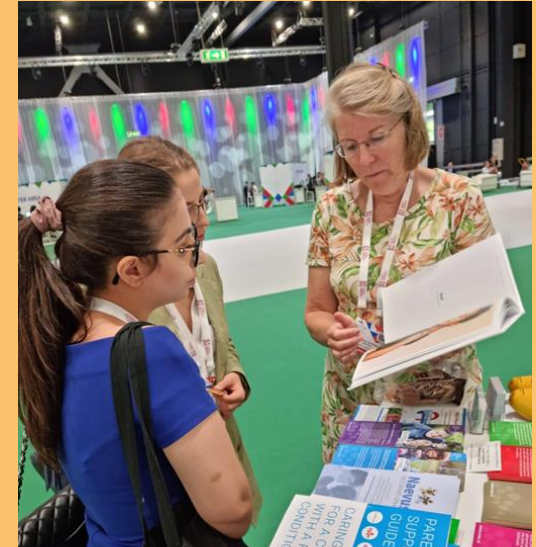
UNIQUE INSIGHTS AND
LIVED EXPERIENCE
MULTIPLE PEOPLE



EMPOWERMENT
AND PARTNERSHIP



ADVOCACY AND
AWARENESS



Challenges



Lack of time
Unpaid voluntary work



Understandable explanation



Awareness



NEVUS OWNERS OUTCOMES REGISTRY



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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