# Naevus International - an international congenital melanocytic naevus initiative

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# Primary aim

To improve the lives of people with CMN, and those of the people who support them

# Change in problems over time

Information scarce, CMN condition not well understood



Information abundant, but not getting to the right people

1980s

2010s

## Current state of play

 Insufficient and incorrect information on CMN reaching patients and doctors and scientists in many countries

Inadequate psychosocial care and information

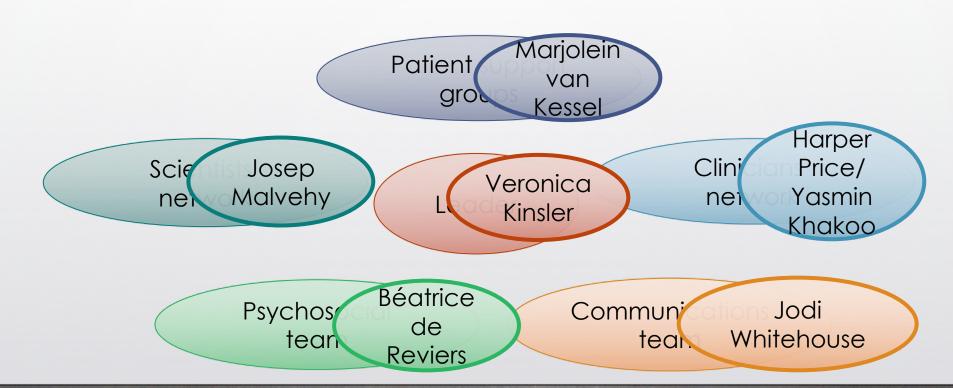
 Problems could be diminished by improved availability of up-to-date information

#### First objectives 2018-2023

Improved access to, and dissemination of, information about CMN, across and between groups of professionals, patients and families

 Extension of those groups to include new members in different countries around the world

#### Structure – equal partners, leader team



# Original set up – slide from 2018

Leader team face-to-face meetings twice a year

 Core team face-to-face meetings once a year, once a year (or more) on Skype

Annual conference

# Clear achievements in the last year

Establishment of a fantastic website

 Amalgamation of all previously separate lists of interested parties into one communications database

 Ongoing in-depth research into psychosocial aspects of CMN

## Clear achievements in the last year

 Complete rewriting/updating of the medical information on the website

Translation of the new medical information into several languages

 A better understanding of what the different groups want and need Some of the fascinating problems we have learned about in this process....

Many doctors and scientists want as much information as possible, to make up their own minds.



Patient groups and non-expert doctors often want definitive guidelines – what is the "one right answer"

Doctors and scientists speak to each other in a different language than they speak to patient groups



Patient groups are/were worried that they will not be given all the information, and that they will not be listened to

Doctors and scientists cannot legally or from a time perspective speak to worldwide patients directly through NI



Patient groups
would like to
have a source
of expert
information that
has a human
face

# So different groups have different perspectives

- this is not a problem
- actually very helpful in moving forward

#### The current structure of NI

The practicalities are not working very well

 It is not growing fast enough for my liking, and not efficiently enough

 We need to rethink the best way to achieve our aims

#### The restructure – online focus

 Website will continue to be the hub – this should be where <u>everyone</u> goes for the latest information on CMN

 All team meetings will be virtual, which will allow them to be expanded

 Conference will be run as a webinar – open to all online – logging on will require sign up to NI

#### The restructure – online focus

 Annual updates of the medical and scientific literature will appear on website, email, and social media after the conference every year

 Campaign to have leaflets given by patients to their doctors, to get them to sign up to NI

#### Conclusions

 Naevus international is a multi-disciplinary initiative, which is going to be its strength, as we continue to communicate better about different perspectives

 An excellent start has been made, and revamping the structure to be more online will be an important step

#### Conclusions

 As the networks grow, all international progress can be communicated and accessible rapidly and effectively

 This should have a direct effect on the quality of care and life for people with CMN, and we will attempt to measure this over the next 4 years

