# Naevus International - an international congenital melanocytic naevus initiative

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Naevus International Inaugural Conference

Paris, 12th September 2018

# 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 is known, but not getting to the right people

1980s

2010s

## Current state of play

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

Totally 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

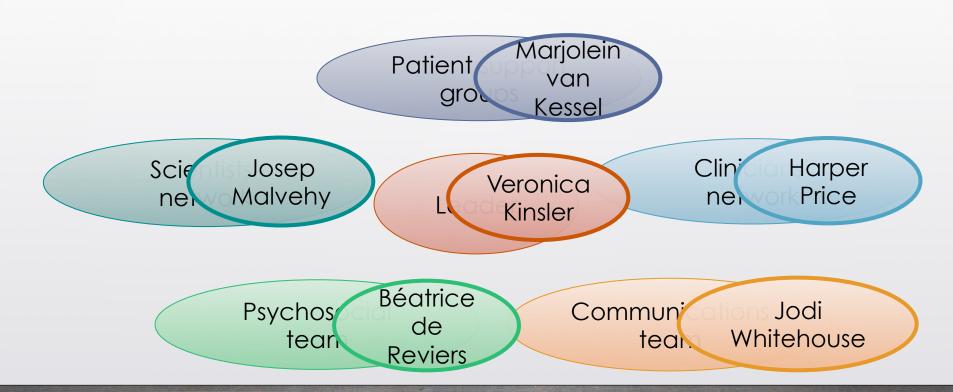
 Extension of those groups to include new members in different countries around the world

#### Vision for the next 5 years

- New treatment or prevention for melanoma
- New treatment for CMN or neurological disease

Instant dissemination to people with CMN, families, doctors, scientists

## Structure – equal partners, leader team



#### Leader team – each built a core team

- Criteria for core team members
  - 3-5 per core team
  - International mix
  - Committed to working (actually working), and attending the NI meeting each year after 2018
  - Knowledgeable about their field

## Patient support group network

Marjolein van Kessel

 Members - all heads or CEOs of national patient support groups



#### Scientists' network

Josep Malvehy

 Members – all proposed or self-proposed scientists or clinician-scientists with an interest in CMN



#### Clinicians' network

 Members – all proposed or self-proposed clinicians interested in CMN Harper Price



## Psychosocial team

Béatrice de Reviers

 Members – clinical psychologists, social workers, lead members of non-CMN organisations such as Changing Faces



#### Communications team

Jodi Whitehouse

 Members – translation advisor, cameraman/ photographer, website designer, public relations advisor, consent advisor, statistician, events organiser



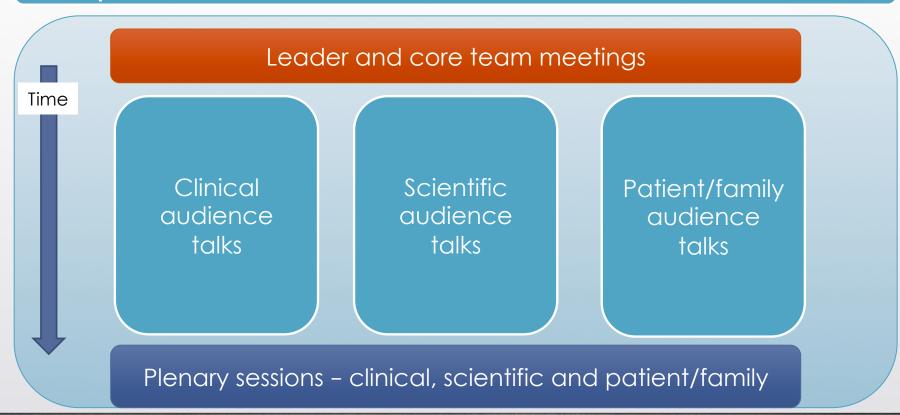
### **Practicalities**

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

## Proposed structure of annual conference



# **Funding**

- Seeking sponsor(s), minimum £10,000 per year needed to run Naevus International
- Sponsor will have recognition and acknowledgment, but no power in decision making or input into teams

## Audit of progress and direction

 In-built audit of the primary aim and the first objectives, analysed annually, reported to leader team

 Each core team has identified outcome measures to assess whether they are making progress

Please fill in the iPad questionnaires which are going around

## Summary

Naevus international is a multi-disciplinary initiative

The first objectives are to establish fantastic networks

 Once networks are there, all 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 5 years

