



# **Clinicians Team- Aims and Challenges**

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## Primary Aims of NI

- ***The primary aim of Naevus International is to improve the lives of those affected by CMN worldwide.***
- 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



# Clinician's Group Core Members

- Harper Price (USA) (lead)
- Pierre Vabres (France)
- Miguel Reyes (USA)
- Yasmin Kakhoo (USA)



London June 2018





## 2018-2019 Goals from London for CT


- Annual research/literature digest newsletter for clinicians, and summary for patients/families – to be sent out after the NI conferences
- Review/update what is currently on website in terms of information for doctors and patients before it gets translated



## Continued Goals for the Clinicians Team (to be discussed in Paris meeting)


- To identify and secure a solid cohort of international clinicians as part of the clinicians group in NI
  - Need input from leaders in other countries and continents about interested parties (Europe/USA ok)
    - Marjolen will refer clinicians from other countries
    - Refer to the NI website, register on website
    - Standard email from communications, prompts to register





## Continued Goals for the Clinicians Group (to be discussed in Paris meeting)

- To further define the roles and goals of clinicians group and develop an “active clinicians” subgroup for those interested in being more involved in projects and initiatives and leads for this group
  - May develop more active group (meet at SPD/AAD if large enough) by late 2019
    - Next meeting
    - How to communicate this
  - Define a future research structure for this group for collaborative efforts (similar to PeDRA) in conjunction with scientific group



## Continued Goals for the Clinicians Group (to be discussed in Paris meeting)

- Develop 1-2 ideas for collaborative projects for the active clinicians group (discuss at Paris meeting) for 2019-2020
  - Required minimal data for registries?
  - Key patient education resources on website from clinicians?
  - Collaborative efforts—define roles and authorship for group projects, what defines a project, effort minimal to be included (Pedra)
  - Research resources for patients





## Challenges

- General communication with larger international audience
- What to do with clinical cases asking for input given new regulations for emailing photos and patient information (HIPPA)?
  - Refer to NI website for list of Patient Support Groups and Clinicians List
  - Local clinicians can reach out to expert clinicians
- Defining structure of the group--evolving

**Thank you!**

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