

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



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About congenital melanocytic nevus (CMN)

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

Occurrence:

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

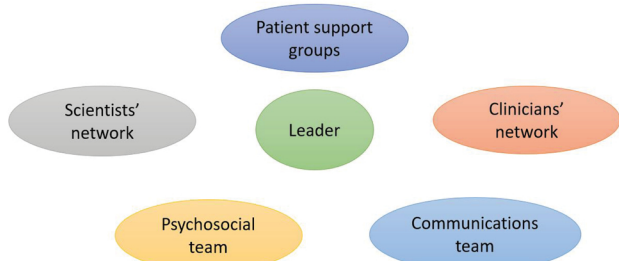
To improve global networking, Naevus Global will continue as Naevus International.

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

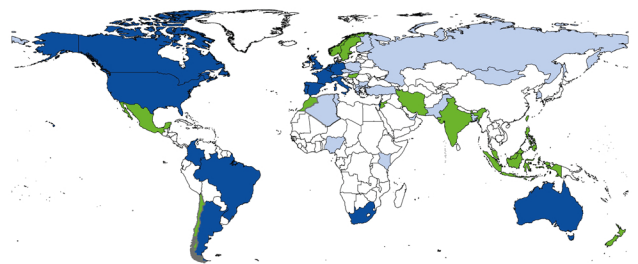
Naevus International



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.