

Naevus Global Conference

June 15-16, 2024

Paris, France

**Notes:** Whitney Casal

**Present:** Whitney Casal, Marjolein van Kessel, Benjamin Löffler, Inbal Engler, Jodi Whitehouse, Ian Chance, Catherine Hong, Beatrice de Reviere, Gabriela Hublova, Quinten de Vries, Veronka Vranska, Lauren Isbell, Christine Ortegat, Francisca Fernandez, Anne Fledderus, Nienke den Hertog, Sieglinde McKeown, Beatriz Boronat Arquer, Evangelia Parzali, Tina Parzali, Lex van der Heijden

## Summary of activities / Major take-aways

Day 1:

- Presentations and updates from individuals and patient organizations.
- Initial presentation of Naevus Global reinvigoration efforts: share survey feedback.

Day 2:

- We edited the proposed mission and vision statements and decided on the final mission and vision.
- We reviewed and edited the organizational values.
- Reviewed and began editing a 5-year Strategic plan.
- We established September 28 as Global CMN Awareness Day (the same date as the founding Naevus Global meeting).
- We identified the need for a Global CMN Awareness Day working group to develop a social media campaign. We proposed it to take place as a once weekly meeting in the 6 weeks leading up.
- We appointed a **Working Group for Global CMN Awareness Day**. We still need to ask:
  - Stephanie Virts / Nevus Outreach, USA
  - Nanette / Nävus Netzwerk, Germany
  - Veronika Vránska / NNN, from Slovakia
  - ?

- We appointed a **Steering Committee** to solidify strategic objectives and short term goals 2025-2030:
  - Whitney / Nevus Outreach, USA
  - Sieglinde McKeown / Nevus Association South Africa
  - Marjolein / Nevus Netwerk, Netherlands
  - Benjamin / Naevus Netzwerk, Germany
  - Inbal / Children of Light, Isreal
  - + Kathy Redmond
- We proposed an annual Naevus Global meeting connected to World Congress on Rare Skin Diseases or the Global Skin meeting, eligible for travel stipends

The steering committee will make a recommendation for member fee at the end of year (In October 2024 so organizations can include in budget planning). A sliding scale will be used based on income and size. A nominal fee for meetings will be determined later.

## Action Items

Immediate:

- The Global Skin Impact Fund 2024 can reimburse the travel and hotel costs of those who are not reimbursed by their own organization. It was proposed that everyone may send their receipts (referring to the Paris trip) to Marjolein. She will then allocate them evenly.
- Please let us know if you are interested in joining the awareness day working group (read more above). This will begin soon!
- Naevus Global will send out information about how becoming a member of Global Skin, if you are a registered organization and are not yet their member.
- Naevus Global will reach out to Kathy Redmond for continued assistance with strategic planning.

Over the next year:

- It was agreed that in the short-term, Naevus Global will remain an unregistered organization. However, we ask that each country investigates what it means to be a legal entity in their own country, and create a list of pros and cons. Then bring this information to the next Naevus Global conference to make a better informed decision.