



Naevus Global General Assembly Summary

The general assembly happened on **9TH December 2014** via Google Hangouts in the presence of a quorum (“the presence of delegates or proxies from a majority of current active member associations”):

- (Australia) **Nevus Australia**, represented by its president, Ms. Michelle Sibbons
- (France) **Association Nævus Géant Congénital**, represented by Mr. Frédéric Barollet
- (France) **Nævus 2000 France-Europe**, represented by Ms. Heather Etchevers,
 - with the proxies of **Naevus Italia**
 - and **Asociación Española de afectados por Nevus Gigante Congénito**
- (Germany) **Nävus-Netzwerk**, represented by Ms. Juliane Stubbe
- (Israel) **Children of Light**, represented by Ms. Inbal Engler
- (The Netherlands) **Nevus Network Nederland**, represented by Mr. Stefan Wilms and Ms. Marjolein van Kessel
- (U.S.A.) **Nevus Outreach, Inc.**, represented by Mr. Mark Beckwith
- (Republic of Macedonia) **Chapter-at-large**, represented by Ms. Biljana Zlatanovska Vladichevska

Observer - (Mexico) **Nevus Mexico**, represented by Mr. Oscar Salcido

Unable to attend: (Belgium) **Flying for Lily**, (Portugal) **Associação Nevo Portugal**, (U.K.) **Caring Matters Now**, (Brazil) **Associação Nevus Brasil**, (Canada) **Association Nævus Québec**, (Argentina) **Nevus Argentina**.

Board report reviews:

Opening: Past year's actions of Naevus Global and those continuing in first half of 2015. See separate report.

(Stefan Wilms - Nevus Netzwerk Nederlands –President)

Condolences conveyed to family and friends on the recent death of Caring Matters Now trustee, Jessica Ma, mother to a child with a giant nevus, who had served for a time as representative of this association to Naevus Global in preparation for the maternity leave of Jodi Whitehouse.

New member associations in 2014 : Associação Nevus Brasil, Association Naevus Québec. These groups had been exempted from 2014 dues, as are all new groups in the year of their official incorporation and recognition by their country's authorities.

Information on <http://www.naevusglobal.org> is now available in additional languages.

Treasurer report: Past year's expenses and income from dues and other sources, and the state of today's accounts. Provisional budget & proposed actions for the upcoming year. See separate report.

(Frédéric Barollet – Association Naevus Géant Congénital – Treasurer)



Member groups that had paid their dues in 2014 were:

- Amutat Yaldehy Haor (Children of Light)
- Associação Nevo Portugal
- Association du Naevus Geant Congénital
- Caring Matters Now
- Naevus 2000 France Europe
- Naevus Netzwerk Deutschland
- Nevus Network Nederland
- Nevus Outreach
- Nevus Support Australia

The dues for 2015 remain :

- 25 euros for members with annual budgets under 10K euros
- 100 euros for members with budgets between 10K and 100K euros
- 250 euros for members with larger budgets

Maintain your group's membership and your vote in global projects at the next General Assembly. Contact fbarollet@naevusglobal.org to ensure payment of up to two years so as to reduce bank fees.

Naevus Global pays dues to of [EURORDIS](#), "the voice of rare disease patients in Europe", to be on their Council of European Federations. Proposals for similar membership and uses for this advocacy platform are encouraged before the next GA.

Projects will be restricted in 2015 to:

- Verbal support for a Global Family Day to be held at EuroDisney Paris in November 2015. We do not have the budget to do more than this, in a way which would be equitable for all members of Naevus Global. For more information, contact Stefania Tedoldi at info@nevogigante.org or Laurence Baert at naevus2000.baert@gmail.com.
- Website maintenance and management of <http://naevusglobal.org>
- Advancing the global patient registry

Registry report : Mark Beckwith – Nevus Outreach – Director of International Registry

To add to the report from November, 2014, the time frame will need some adjustment with everything probably later (no date stipulated), particularly for the professional gateway, while the patient gateway may be underway earlier.

Dr. Céline Eggen from the Netherlands, pediatric dermatologist undertaking a Ph.D., has obtained a grant from the European Academy of Dermatology and Venereology to develop a core set of standardized outcome measures to incorporate into the developing registry and ultimately, guide treatment decision-making. The grant application stipulates that inclusion of these measurements in the registry is by December, 2016, which implies that the rest of the registry infrastructure must be in place before that.

Mark Beckwith further reported that after a recent December meeting with Dr. Miguel Reyes-Mùgica and Dr. Cláudia Salgado in Pittsburgh (USA), there were no significant obstacles on the ethical front to



constructing a registry with a dual web-based interface, between this and the other centers potentially involved: Dr. Ashfaq Marghoob at Memorial Sloan-Kettering Cancer Center, New York (USA) , Dr. Suzanne Pasmans at Erasmus MC, Rotterdam (Netherlands); and Dr. Josep Malvehy of the Hospital Clinic of Barcelona (Spain), who at the time of writing awaited “details of cost estimates, feasibility and time frames” to give final approval for participation.

The General Assembly voted unanimously in favor of the following:

- Approval of the list of proxies sent to the Secretary for this General Assembly
- Approval of 2014 activities and budget as reported
- Approval of 2015 projects as reported

Other topics for votes

Approval of official logos for 2015. The proposed designs were accepted provisionally until the organization of a design contest to be opened to all constituents of member associations. Designs will be submitted by the end of March, 2015, and chosen by popular vote on the [Naevus Global Facebook page](#) in the following month and final ratification by the Board, at which time they will be used immediately.

Must feature in the design: “Naevus Global” with no abbreviations, few colors, a logo that can be used anywhere in the world without cultural misunderstandings, but making allusion to the global aspect of the federation. Specifics for resolution, copyright etc. will be mentioned when the contest is opened.

The General Assembly voted unanimously in favor of the following:

- Establishment of an Internet/website committee of three members - Alan Sibbons (Nevus Australia), Heather Etchevers (Naevus 2000 France-Europe), and **a third volunteer still sought** - who will make decisions for the website and the redirection of e-mail communications to contact@naevusglobal.org.
- The Facebook page for Naevus Global, to promote the website and Naevus Global activities. The need for a similar Google+ page was discussed and dismissed.
- Acknowledgement of the existence of unincorporated, informal discussion groups in the following countries or regions, and the need to contact each on behalf of the federation to propose aid and inform them of representation through the chapter-at-large: : [Mexico](#), [New Zealand](#), [Norway](#), [Sweden](#), [Hungary](#), [Taiwan](#), [English-language Canada](#), [South Africa](#), and [Middle East/United Arab Emirates](#).
- Establishment of a Naevus Global Scientific Advisory Council (SAC) chaired by Heather Etchevers, to offer expert opinion to the Naevus Global Board of Directors. This will allow it to orient patients and their families seeking assistance when the situation falls outside the collective experience of the Board, and to recommend participation, financial or otherwise, in research projects to one or more member groups. All member groups are encouraged to submit names of experts anywhere in the world who might be approached to participate, with no guarantees.



- Approval of a new Board of Directors:
 1. **Michelle Sibbons** for **Nevus Australia** (msibbons@naevusglobal.org)
 2. **Frédéric Barollet** for **Association Naevus Géant Congénital** (fbarollet@naevusglobal.org)
 3. **Marjolein van Kessel** for **Nevus Netwerk Nederland** (mvankessel@naevusglobal.org)
 4. **Inbal Engler** for **Children of Light** (iengler@naevusglobal.org)
 5. **Biljana Vladichevska** for **Members-at-Large** (bvladichevska@naevusglobal.org)
 6. **Mark Beckwith** of **Nevus Outreach** as director of the International Registry (mbeckwith@naevusglobal.org)
 7. **Heather Etchevers** of **Nævus 2000 France Europe** as chair of the SAC (hetchevers@naevusglobal.org)

The General Assembly unanimously approved the following motion:

Following the resignation of Stefan Wilms as President, the Board will establish a new Executive Committee after ratification of the new Board of Directors, but no later than 31 December 2014."

The Board establishes a new Executive Committee consisting of Michelle Sibbons, President; Inbal Engler (with the help of Heather Etchevers), Secretary; Frédéric Barollet, Treasurer.

The General Assembly unanimously approved the following motion:

The next General Assembly will be held in May or June, 2015, and annually thereafter.

Michelle Sibbons extended an invitation to anyone who would like to attend the Nevus Australia conference in January. Unfortunately they are unable to offer financial assistance.

With no other topics raised, the meeting was adjourned.


 Stefan Wilms, president
 
 Inbal Engler, secretary

15 December 2014