



## General Assembly (GA) minutes from June 6<sup>th</sup>, 7 pm UTC/GMT

**Attending:** Pedro Rolando Lopez (Columbia), Jodi Whitehouse (England), Marica Cislighi (Italy), Corrado Gianì (Italy), Siggì Nierich McKeown (South Africa), Paul Coleman (USA), Biljana Zlatanoska (Chapter at large), Ingeborg Cappelen Lindheim (Norway), Taylor Scott (USA), Evangelina Parzali (Greece), Heather Etchevers (France), Inbal Travis Engler (Israel), Marjolein van Kessel (the Netherlands)

### 1. Opening

Welcome to attendees.

Leading the meeting: Marjolein van Kessel

Taking notes: Inbal Engler, Heather Etchevers

Naevus Global members attending: 6

Heather (Naevus 2000), Jodi (Caring Matters Now), Inbal (Children of Light), Biljana (Chapter at large), Corrado and Marica (Naevus Italia), Taylor (Nevus Outreach)

Proxies: 2

Frederic (Association Naevus Géant Congénital), Francesca Fernandez (Asociación Española de Nevus Gigante Congénito [AsoNevus])

Not attending: 4

Nevus Australia, Nävus Netzwerk (Germany), Nevus Network Nederland (the Netherlands), Flying for Lily (Belgium)

Marjolein did not vote on behalf of NNN, not considering herself authorized as she is no longer part of the NNN Board and did not receive a mandate for that purpose.

Total voting member groups: 13. There was therefore a quorum to vote. This quorum (more than half of 13 members with or without proxies) was interpreted conservatively as adequate for the purposes of approving actions of the previous administrators and for voting in new Executive Committee positions, had there been candidates (more than half of 13 members) but insufficient to statute on agenda item 4, as explained below.

### 2. Report by outgoing president

Michelle (Australia) had been president since the previous GA (December 2014; the report at this link: [http://www.naevusglobal.org/images/user\\_images/1-GA%2009-12-2014%20report-signed.pdf](http://www.naevusglobal.org/images/user_images/1-GA%2009-12-2014%20report-signed.pdf)) but resigned formally in February, 2017, requesting to remain on the Board without a nominal position. The following report was therefore prepared and presented by the interim president, Marjolein, with assistance from the remaining Board.

Inbal Engler tendered her resignation as secretary in autumn of 2014, pleading too many duties with her national group and family concerns, but has remained in truth the Secretary even since that time. The position has been open to other candidates since.

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✉ [contact@naevusglobal.org](mailto:contact@naevusglobal.org)

 [www.naevusglobal.org](http://www.naevusglobal.org)

 [www.facebook.com/NaevusGlobal/](http://www.facebook.com/NaevusGlobal/)

Jodi had resigned from the Board earlier in 2014, for similar reasons, but Caring Matters Now remained a member of NG.

As the Board required at least three and at most seven active member delegates, and Heather wished to no longer represent Naevus 2000 France-Europe to Naevus Global in 2015-2016, she also resigned as Board member and retained the status of advisor.

The constitution of our Scientific Advisory Committee (SAC) took place in January, 2015. Dr. Heather Etchevers was chair. The SAC chose, and we published on our website, a bibliography of their preferred scientific and medical journal papers about CMN and NCM at the time, with links to each abstract. It is at this link: [http://www.naevusglobal.org/bibliography\\_id222.html](http://www.naevusglobal.org/bibliography_id222.html). Full-text reprint requests as always to [contact@naevusglobal.org](mailto:contact@naevusglobal.org).

There will be an Expert Meeting on August 26<sup>th</sup>, 2017, in Denver, Colorado (USA), with three objectives.

- providing a scientific update to the professionals present,
- beginning the process of issuing a consensus statement on therapeutic protocols for people with CMN,
- setting a date for a next meeting.

The chairs will be Dr. Veronica Kinsler, Dr. Josep Malvehy and Dr. Harper Price. Naevus Global representation will be ensured by Mark (see below).

#### Website:

We have increased the number of languages available on our website. Currently there is professionally written and vetted layperson-friendly information available in 10 languages.

Website traffic: Access to the web site has increased every year since Naevus Global was founded, as follows:

2013 **839** page views

2014 **8 363** page views

2015 **9 772** page views

2016 **10 504** page views

2017 **6 850** page views through May 31 = projection of 16,440 page views in 2017

After a Board meeting in March, 2015, Michelle centralized short biographies of each of the Board members and posted these periodically on the Naevus Global Facebook page. We commissioned a logo from a professional graphic artist in the Netherlands.

### **3. Report by the Treasurer**

Frédéric transmits that no expenses were incurred over the last period except for the NG logo in 2015, and banking management costs.

No association paid its dues for 2017. Our dues had remained unchanged since the report at our 2015 General Assembly, but as was pointed out by prospective members later, these dues and who should pay them were not clearly visible on the Naevus Global website:

- 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

Bank balance as of today is € 6 580.38.

Frédéric is resigning his treasurer duties in both ANGC and Naevus Global and wishes us all well in our future ventures.

No candidate for the position of treasurer made themselves known before or during the GA.

This has left us without any Executive Committee (president/secretary/treasurer), and no candidates, except Marjolein to continue as president.

#### 4. **Motion to dissolve Naevus Global**

The way the organization has been set up does not work sustainably and we do not meet our legal obligations.

Positives:

- It is of net mutual benefit to connect patient advocates at an international level
- The website with its many translations of vetted information is a popular resource
- The Scientific Advisory Committee (SAC) is a helpful, reassuring, underutilized resource

Negatives:

- People on the NG board are often involved in their local support group as well, diluting their focus on NG priorities
- There has been persistent confusion since our founding about the three levels of participation: membership *versus* presence on the Board of NG versus the Executive Committee (president/secretary/treasurer). Furthermore, the responsibilities of Executive Committee positions as specified in the statutes were not clear or not fully assumed. The possibility to name a different volunteer than an officer from each patient group to represent it was not often used, spreading volunteers too thin.
- Only patient groups rather than individuals were allowed to be members, discouraging interested parties from participating actively when there was already a person from that patient group ostensibly present to represent it
- The yearly reports, GA, and board meetings have been difficult to organize, partly because of the language barrier for many non-English-speaking countries, partly (we presume) because of priorities
- Naevus Global is registered in Marseille, France. Its paperwork has been and continues to be administered by Heather and Frédéric. However, in the absence of a GA in 2016 with presidential and treasurer's reports to voting members, and unable to provide this annual paperwork to Marseille city hall, our mailbox privileges were revoked last year. This has placed NG into a legal limbo.
- Meanwhile, Heather resigned from the Board to no longer represent Naevus 2000 France-Europe to NG or in theory, to assist the Secretary (Inbal), though Heather remained in her capacity as chair of the SAC and both Secretary and assistance continued volunteering well beyond their respective resignations for lack of other candidates to do the necessary tasks. Likewise, Frédéric resigned as Treasurer in June, 2016, in preparation for potential new officer candidates to present themselves at this year's GA. However, none have been forthcoming
- After their first year in existence, member associations of Naevus Global should pay dues of at least €25 a year. But as many associations continue to not have income, and as they were not pursued lately for their annual fees by the treasurer, these were paid only irregularly. This has led to ambiguity about what it takes to have voting status.

The acting Board moves to dissolve Naevus Global from its current form to a less formal working group and to open its membership to individuals. Marjolein would like to organize a meeting in

the autumn and encourages all interested people to contact her at [mvankessel@naevusglobal.org](mailto:mvankessel@naevusglobal.org).

With respect to this motion, conservative interpretation of the statutes is that voting by proxy shall not be allowed for motions including dissolution - meaning that we did not have a quorum for this purpose on June 6<sup>th</sup>, 2017. Therefore this vote will happen online with an extraordinary GA among voting members only. Results will be appended to this report.

Maintaining the Naevus Global website: Mark has offered to continue management of the website as an individual, rather than representing Nevus Outreach.

Liquidation of the Naevus Global bank account:

Vote to transfer the remaining treasury balance upon liquidation to Nevus Outreach, Inc., to offset partial development and maintenance costs of [naevusglobal.org](http://naevusglobal.org) website through the end of 2017.

We discussed with Taylor as designated representative of Nevus Outreach, that the equivalent of **3 580 euros will be earmarked** for expenditures relative to any meeting initiative that can be justified to Naevus Global members, within the framework of **improving cross-border care for CMN patients**, in exchange for a written report and without exceeding the equivalent of 500 euros per person.

Taylor confirmed that these funds could be earmarked or put in a separately managed bank account. The money would always be available for Naevus Global initiatives, even if Mark or Taylor were no longer personally representing Nevus Outreach.

Vote: To transfer all remaining Naevus Global funds to Nevus Outreach and close our current bank account: **unanimous in favor** (8 votes)

Vote: To mandate Naevus Global to cover participation-related expenses of € 3 580 and retain the other € 3 000 to offset website development and maintenance costs through the end of 2017: **unanimous in favor** (8 votes)

## 5. The current president presents ongoing and future goals

No concrete actions could be proposed at this time to support other countries in organizing advocacy, aside from contact and discussion through the existing infrastructure.

Marjolein affirmed her desire to update and commission more translations of the medical information available on the NG-website, but the need and choice of languages were not discussed at this time.

Establishing and publishing reference lists of sites for patient care was discussed. These would list medical centers demonstrating expertise in CMN and NCM in the realms of dermatology, plastic surgery, genetics, neurology and psychology. They would complement and expand the coverage offered by the European Reference Network on Rare and Undiagnosed Skin Disorders (ERN-SKIN) as it is currently centered on only some of these disciplines, and only within Europe. (Individual physicians cannot be endorsed by Naevus Global.) As a first measure, Marjolein will approach the ERN-SKIN and join Jodi as a patient advocate with the corresponding ePAG (European Patient Advocacy Group).

Paul Coleman (Nevus Outreach) commented that the SAC could also help compile a list of their recommendations for regional centers or clinics to which people with CMN syndrome could look for expertise.

- a. Working toward worldwide standards in CMN syndrome patient care:
  - i. Mark is already representing NG with the professional CMN and NCM experts in setting up treatment guidelines, and proposed to continue for 2017-2018. Jodi is also involved through Caring Matters Now and working closely with Dr. Veronica Kinsler, a major professional organizer, and will remain so over the same period.
  - ii. Marjolein is willing to represent Naevus Global and Jodi already represents Caring Matters Now to the ERN-SKIN through Eurordis' ePAG. Therefore two advocates will promote CMN-related concerns, of the many other rare (and often hereditary) skin conditions possible.
6. No **prospective budget** could be determined or put to a vote, in the process of dissolving/refounding Naevus Global and without a treasurer. Likewise, voting for officers in the absence of candidates and the imminent dissolution of the statutes was not held.

## 7. Other questions

- a. Organizers to arrange and establish an agenda for in-person meetings between three or more member groups.
  - World Pediatric Dermatology Congress, Chicago: Mark will attend for NG
  - the International Pigment Cell Conference in Denver: Mark attend for NG
  - Global Skin congress September: Marjolein may attend. **Are there other volunteers?**
  - Meeting in Palma de Mallorca, 19–21 October 2017: there will probably not be a meeting on CMN specifically as Dr. Malvey, who had proposed to organize it, can no longer attend.
  - the 18th European Society for Pediatric Dermatology Annual Meeting in London, 7–9 June 2018. This is a good date for an Expert Meeting with NG participation, though it is too early for more. Likely to be hosted with assistance from Caring Matters Now.

Renew 2018 membership of Naevus Global in EURORDIS and its Council for European / International Federations, at 25 euros/year.

**Approved unanimously (6 votes in favor, none against, none abstaining).**

As Naevus Global will still exist, though not in its current form incorporated in France, we anticipate that it may still be a member of Eurordis (and its Council of European /International Federations), initially. Other groups are also members from outside of Europe.

- b. Renewal of Naevus Global's Scientific Advisory Council. Heather reported:

Our current roster of 40 experts accepted to volunteer their expertise as advisors to Naevus Global (NG) **and any of its member associations** in January, 2015. Just before this GA, two additional members were nominated and accepted, rounding out representation in pediatric plastic surgery: Dr. Bruce Bauer and Professor Clemens Schiestl. Their bios will appear shortly on the website at [http://www.naevusglobal.org/scientific-advisory-council\\_id180.html](http://www.naevusglobal.org/scientific-advisory-council_id180.html) .

The purpose of the SAC is to offer expert opinion to Naevus Global in order for it to do the following:

1. orient patients and their families seeking assistance when the situation falls outside the collective experience of the volunteers directing NG;

2. recommend participation, financial or otherwise, in research projects to one or more member groups

Since its creation, only a few questions relative to the first purpose have been forwarded. No requests have been sent from member groups without a representative on the Board, and rarely even by them. Therefore, the experts are not tired of us and still glad to be on call, as it were. It may be important to remind members of NG of this possibility, although under the previous statutes any such questions would have been filtered through the patient advocate representatives. Nonetheless, Heather may be contacted directly at [hetchevers@naevusglobal.org](mailto:hetchevers@naevusglobal.org); this information may be made more visible on the website.

Questions to the SAC are redirected to only one or a few members at a time by the chair as needed. In this manner, being on the SAC takes little to none of any given advisor's time, depending on the needs of the NG member groups and the number of experts present in each discipline. This is analogous to the relationship between an editor for a biomedical journal and the expertise of the corresponding editorial board.

Heather told the council that as chair, she will report the advice back to Naevus Global. Both the response to the question and a summary in a public annual report to the GA or another format as needed. The expert's name will be redacted unless they request otherwise.

Dr. Josep Malvehy had been willing to be chair in January, 2017, but has since changed his mind due to other commitments. No other volunteers had been forthcoming in a survey in December, 2016. Heather will therefore continue to chair this committee for the time being.

That survey was designed to gauge interest in professionals' self-organizing a meeting in conjunction with another conference to discuss consensus guidelines for treatment. This exercise in part led to the upcoming satellite meeting in Denver at the IPCC.

New members are nominated by current members, as has been the case from the outset, and invited by the chair pending a brief questionnaire. Patient groups may submit names to be considered for nomination by the SAC, but invitations are issued after internal recognition of their complementary expertise in a domain relevant to the care or understanding of CMN syndrome in its many forms. Naevus Italia was interested in nominating two experts from their national SAC.

#### Comments :

- Pedro (Columbia) would very much like to be informed on and involved in Naevus Global activities
- Siggie (South Africa) asks the same and announces their new website will soon be online
- Both groups should feature on an updated Naevus Global webpage and will send relevant information to Mark
- Corrado announces two international Italian professional meetings in Bologna and Rome in September/October 2017 and would like to invite someone from Naevus Global to speak. It was not clear if that should be in Italian, English or another language. Bologna <http://www.sidemast.org/evento/479/> and Rome <http://www.siderp.it/evento/30/>.
- Inbal has just organized a large Israeli family event and posted pictures on Naevus Global. She proposes reviving a special fund-raiser/consciousness-raiser launched by Yoav Goan last

year to have people add beauty spots to their body, with the idea of transforming it into an international CMN awareness day.

[https://drive.google.com/file/d/0B89\\_urx4HrNBaTB0SHktTkhTTzQ/view](https://drive.google.com/file/d/0B89_urx4HrNBaTB0SHktTkhTTzQ/view)

Heather asked if people with CMN might not be bothered by the “imitation” aspect, and turned to Jodi, who thinks it’s an excellent way of raising money and awareness

- Corrado will help administer our Facebook page
- Ingeborg (Norway): did not know there was a fee to be a member of Naevus Global. It was not clear to her on the NG website which associations were voting members and which not. Pedro asks how new associations can be included in NG and we left this question to be resolved in the autumn once the status of the current group is resolved.
- Heather intended, but forgot, to share a link to a TEDx talk by a woman physician with a giant CMN herself, Dr .Béatrice de Reviers, about her tools to deal with how others look at her. Dr. de Reviers developed the talk with assistance from materials made available to Caring Matters Now by the British advocacy group, Changing Faces. The video is currently subtitled through efforts of NG members, particularly Naevus 2000 France-Europe (French), AsoNevus (Spanish), and unknown volunteers from Sweden and Italian. Subtitles may be chosen by placing the mouse over the video and choosing an option in the lower right corner. This video may be embedded on any NG member group’s website (as is the case for AsoNevus in Spain) or on the NG website itself.

<https://www.youtube.com/watch?v=W6VKUIWVNUA>

**8. Close of General Assembly 2017 22:30**

Decisions	
<ul style="list-style-type: none"> <li>- Imminent Extraordinary General Assembly online with vote on dissolution</li> <li>- transfer remaining funds to Nevus Outreach and liquidate current bank account</li> <li>- mandate Nevus Outreach to cover participation-related expenses for NG representatives as specified above and offset some NG website expenses</li> </ul>	

Task list	
- interim president Naevus Global	Marjolein
- maintenance of Naevus Global website	Mark
- interface with Dr. Veronica Kinsler on guidelines	Jodi
- interface with other CMN and NCM experts on guidelines	Mark
- represent Naevus Global to Eurordis ePAG for ERN-SKIN	Marjolein
- represent Caring Matters Now to Eurordis ePAG for ERN-SKIN	Jodi
- represent NG to World Pediatric Dermatology Congress	Mark
- represent NG to the International Pigment Cell Conference	Mark
- represent NG to the Global Skin congress	Marjolein

Comments/questions
<ul style="list-style-type: none"> <li>- We should ask members of the SAC to each provide a list of five recommended places for CMN families to seek medical assistance in their country/region</li> <li>- Inbal (Israel) shared an initiative by Children of Light’s Yoav Goan for awareness- and fund-raising, to be considered as an annual international CMN awareness day gesture each July. More information forthcoming.</li> <li>- Corrado shared links to two upcoming international conferences, for which the professional content appears to be in Italian, but to which Naevus Italia would like to invite other members of NG to speak of their patient group experiences.</li> <li>- Need for more animation on the NG Facebook page - submit content with an international impact</li> <li>- Need to make members of Naevus Global more visible to each other.</li> <li>- Encourage more associations - formal or not -and possibly individuals, to join.</li> </ul>

This report will be made publicly available on the naevusglobal.org website and elsewhere, as of June 21<sup>st</sup>, 2017.

With no other topics raised, the meeting was adjourned.

*Marjolein van Kessel, acting president*



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*Inbal Engler, secretary*



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20 June 2017

## Motion to dissolve Naevus Global



**The following members (in parentheses, representatives casting the vote) moved by Extraordinary General Assembly to dissolve Naevus Global under its current statutes as of 20 June 2017 :**

Asociación Española de Nevus Gigante Congénito, Spain (Francisca Fernandez)  
Associação Nevo Portugal, Portugal (Rosa Fernandes)  
Association Nevus Geant Congenital, France (Frédéric Barollet)  
Caring Matters Now, UK (Jodi Whitehouse and Lucy Hardwidge)  
Chapter-at-large (Biljana Vladichevska)  
Children of Light, Israel (Inbal Travis Engler)  
Naevus 2000 France-Europe, France (Laurence Baert)  
Nevus Outreach, USA (Paul Coleman and Mark Beckwith)  
Nevus Netwerk Nederland, the Netherlands (Judith Taen)

**The following members voted against this measure:**

none

**The following members abstained:**

Naevus Italia, Italy (Corrado Gianí)

**The following members did not participate in either general assembly:**

Flying for Lily, Belgium  
Nävus Netzwerk, Germany  
Nevus Australia, Australia

## Conclusion:

Naevus Global will be dissolved as a non-profit association legal entity officially registered in France, in accordance with its statutes. These will conclude as of the final liquidation of assets as determined in the General Assembly of 6 June 2017.

**Initial responses to these questions:**

*What should be the new missions or structuration of Naevus Global? Which projects and initiatives will you and the people you represent support with your volunteer efforts, and how? Please discuss ways to be involved with other members of your patient advocacy group.*

Continued support for [the] world's patients, providing **information and guidance** for new and existing patients and parents. I don't have an idea on how to exist as a legal entity but I would really like to see continued organisation on [a] global level. I would like to continue to be involved in some form because I think that the existence of Naevus Global is most beneficial in **organising knowledge** from around the world.

**Development of Spanish-language resources** to share with Columbia, Argentina, Mexico and beyond.

**Increase awareness;** have international **research**.

Harmonise Naevus Global with other local associations- **involving representatives in local country initiatives.**

Would like to see NG become a support umbrella helping patient groups to function to the best of their ability: **sharing information, support materials** etc. Caring Matters Now can help in this respect. The medical advisory board should continue as it stands as this is invaluable to further **advancing patient care.**

My feeling is that NG should be a forum to allow all the patient support groups to be there and support one another, allowing the **sharing of ideas, materials, experiences.** We have tools and materials, processes and procedures we would be happy to share with the group.

A group dedicated to the open source of information (scientific, clinical and administrative) to **support** the nevus community globally. A **resource** (an information nexus) for **scientists, providers and national/local patient support groups.**

With no other topics raised, the online meeting was adjourned.

Marjolein van Kessel, acting president



Inbal Engler, secretary



20 June 2017