

**Naevus International core team meeting minutes**

**Wednesday 6<sup>th</sup> June 2018, 11am-1pm**

**Queen Elizabeth II conference centre, London**

**Attendees:** Veronica Kinsler (VK)(Chair), Dr Béatrice de Reviers (BR), Dr Josep Malvehy (JM), Dr Harper Price (HP), Mrs Marjolein van Kessel (MK), Mrs Lucy Hardwidge (LH) (for Jodi Whitehouse)

**Apologies:** Mrs Jodi Whitehouse

**1. Review of NI aims and ethos**

All in agreement of aims of NI as laid out at Denver IPCC meeting and on website

JM - agreed with VK plan to work with a small core teams to allow easy manageability and to keep costs down

VK - one key objective initially is to work together to assist those smaller CMN organisations/countries without a CMN organisation to allow information to be shared and accessible, rather than trying to improve things in countries where the level of access to information is already good

JM - not to be too ambitious initially - ideally need to bring all countries in line with one another before can start doing other things

VK - develop a similar wealth of information across the board and to achieve this we need to work hard to establish a network first. We currently have a network of a few wealthy countries but we need to ensure we reach out to those smaller, less established organisations/countries

MV - suggested the potential to use the link with Rare Diseases to develop our network. Referring to the NI poster, it shows clearly on a map where we have established organisations, those with just a Facebook group and those with just an individual or small cluster of individuals

VK - we should update this map each year in the hope we will see a wider spread or established organisations; our NI network. This would be one good measurement of whether we are achieving our aims

**2. Review of NI structure including key team members for each of 5 teams**

VK – the structure of NI needs to be cross-disciplinary, working together to develop an equal network, not biased towards or away from professionals or patient groups

VK – leadership group now established along with core teams. Ideally need to try and ensure different countries represented in each core team

VK – to keep costs low at this stage the leadership team will meet twice a year and the core teams once a year. The leadership meetings will coincide with the annual NI Conference and the EADV or AAD Conference, or possibly ESPCR or other. The core team meetings will coincide with the annual NI Conference if possible, however if not

practically possible it would be acceptable for a core team to meet at a time more suitable to themselves if necessary. Ideally however they need to attend the conference, and this should be understood when people accept membership of a core team. Reasonable expenses for core team members to attend the NI conference will be paid by NI once a year

VK – when emailing only copy in the whole of the leadership team when necessary, otherwise communicate freely amongst yourselves to reduce unnecessary emails

HP – key tool to facilitate the main aim will be the website? VK – confirmed yes. This will be hub of all information. Individual emails to NI cannot be answered other than by the email administrator (yet to be confirmed by Comms team but may be Michelle Sibbons) who will use standard reply emails for this which link to the website. The organisation is too global and we are too small a team to be able to answer individual emails personally

### **3. Introduction of the Teams**

Brief presentation from each of the 5 team leaders

## **Mrs Marjolein van Kessel**

### **Leader of patient support group network**

Core Group:

Corrado Giani

Siglinde McKeown

Paul Coleman

Pedro Rolando Lopez

MV – reported that research is of key importance to patients

MV – Joined associations; Eurodis, Global Skin & Melanoma Patient Support.

MV – introduced Share4Rare who are building a platform to facilitate the sharing of information on cutaneous melanoma with clinicians & physicians. Great tool to use as a guide

MV – asked if we will re-name current Naevus Global Facebook page or start a new one?

VK felt a new one would be the best way forward, as Naevus Global is a PSG-led group, that will apparently continue to function, whereas NI is a multidisciplinary group and has different aims. This was agreed by JM and other leadership team members

MV – it would be good to have the website multi-lingual. All agreed. Top 10 languages in the world identified via Google. Top 5 plus common European languages (only because we have easy access to people who know European languages and currently many members from those countries) would be the first priorities in the first two years, then all top 10 by the end of the 5 year term of leadership and core teams

MV – asked who would facilitate the NI newsletter to members of NI? VK has asked MV to identify what should go into that newsletter, with other leadership team adding suggestions, and Comms team will send it out

MV – Is there any budget to cover costs for attending networking events? VK stated that MV NI representation at some conferences is important. VK suggested that MV looks at the two most important meetings relevant to the aims of NI each year and that NI will facilitate a budget of £1,000 per year for MV to attend

MV – Can we consider becoming officially registered to allow easier connection with other organisations and to help with networking. To be discussed later

VK – MV has a great global view which will be very helpful in developing NI, thinking about the healthcare and psycho social impacts. We cannot improve healthcare training or availability, this is beyond the scope of NI, but we can provide the information to patients and families which can share this with the medical professionals and direct them to the website for further information

HP – asked about the SAC scientific advisory committee of Naevus Global as most of leader team on it. Agreed together that seems sensible if we are trying to run NI that we step down from NG SAC. Individuals will do this themselves. MV can of course continue to be involved in NG if she has time and wishes to, but may find that running the PSG arm of NI is enough

JM – This is just the beginning of the story and we can look into registering as this will also help with sourcing trials, seeking funding. The registration process is different in each country.

### **MVK action points**

- 1) Investigate registration
- 2) Identify two most important conferences to attend to promote NI, likely to include EADV patient village

### **MVK and the PSG team – AGREED AIMS FOR THE YEAR AHEAD**

- 1) Registration of NI in whatever form is agreed to be best by leadership team after investigation
- 2) Production of an annual newsletter for NI
- 3) Coordination of translation of existing materials on website – top 5 languages plus the common European languages in the first 2 years would be ideal

## **Dr Harper Price**

### **Leader of clinicians' network**

Core group:

Pierre Vabres

Sven Krengel

Miguel Reyes-Mugica

VK - MV and everyone else to share with HP the list of physicians from other countries that they have gathered from networking and supporting individuals across the world. We want to build a full and non-restrictive list of physicians. VK states there should be no criteria on the number of cases seen of CMN, even none, as we are not assembling an expert group, we are assembling a dissemination and education list of any doctor interested in CMN

MV – concerned about the support for families, we need to learn from each melanoma case. VK says PSGs should continue to support the families, and many of the leader team get to hear of most melanoma cases from the people we currently know, and that establishing and expanding the physicians' group will ensure more contact is available

HP – direct all physicians to the website to register. Whoever is managing emails will have a library of standard emails to send out; standard welcome email etc.

MV - Naevus Outreach Facebook page has a list of physicians' contacts, but no email address. It was suggested MV get the list and send to HP and we can consider a mailshot to see if they would like to register

HP – aims to develop an active Clinicians group. PEDRA group has a great structure for future development

HP – thoughts on reaching clinicians is to do something similar to SDP newsletter – once a year, great resource tool in reaching clinicians – this would be a research digest of the year's publications, which would be a condensed version of main research findings relating to CMN. In order that it also be available for patients too, HP to make a lay- or patient-friendly version as well once a year. These would be sent out by Comms team

HP – action points

- 1) Be the contact point for everyone else to send through any clinicians known about who might be interested to be member

HP and the physicians team – AGREED AIMS FOR THE YEAR AHEAD

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

## Dr Béatrice de Reviere

### Leader of psychosocial team

Core group:

Saskia Sanderson

Lorraine Joly

BR – has been working on the psychosocial impacts on children with CMN. Amongst many things have identified the factors contributing to distress, which are not necessarily the ones we think they are, & looked at the actions and interventions that work

BR – the movie Wonder has proven a great tool and has connected with the children

BR – using findings the “Tous en Piste” comic book has been developed and is available now for children with CMN or a child appearing different. But it has been recognized that the parent must read the book with the child to assist and support them and answer any questions

BR - Taking the Tous en Piste to Therapeutic Education – face to face programme.

Funding secured for the programme and are running a study to establish outcomes.

VK – suggested having the book at the Caring Matters Now UK Conference in 2019

BR – created a workshop for schools to educate on accepting differences. LH asked if this is part of the school curriculum in France; BR stated no!

VK - Almost no research in psychosocial aspects of CMN, new area of expertise, and therefore this core group is unlike the others. This is not yet something on which we have lots of information to disseminate

VK - Great to set this up and establish this in France with Beatrice's expertise and skills, then measure the success, see what is definitely working, before rolling out the information Internationally. In the interim would be good to put on the website some basic information about the psychosocial side, links to websites such as Changing Faces where good and reliable information is available

BR – action points

- 1) Speak to candidate speaker for NI conference
- 2) To continue current activities and research into best psychosocial support and tools for people and families with CMN

### **BR and psychosocial team – AGREED AIMS FOR YEAR AHEAD**

- 1) Organisation of “Tous en piste” into English – possibly consider online version rather than book as would be cheaper and more accessible?
- 2) Write one short page for website with links to useful other websites concerning visible difference (and possibly point 3 below)
- 3) Start discussion about whether there should be recommendations for parents/teens/children on what to put about themselves/their children on Facebook when they have CMN – team to liaise with JW and MVK for their ideas if necessary

## Mrs Jodi Whitehouse

### **Leader of communications team**

Core group:

Kathy Wright

Michelle Sibbons

MK – doesn't like the flags of the countries, would prefer logos. VK – thinks should leave flags as some organisations don't have logo, or people searching wouldn't know what the logo was for their country, and everyone can be easily searched in this way

MK- [naevus.org](http://naevus.org) said thank you, they are pleased to be mentioned on the NI website

HP- identify number of members and physicians in the physicians group on the homepage of the website – like a live count

VK- show date on the website of when it was last updated

VK – Research page - Considered showing pub med search of all publications with disclaimer – in fact would be better just to have a link to PubMed so that people could search for CMN themselves (or will get too long very rapidly, and we are going to have a research digest in any case. Annual research digests should be available on that page.

Legal disclaimers that we are not recommending or supporting any particular research or publications, or physicians, or a substitute for seeing a doctor, may be required on each page – Jodi to look into this

LH/JW – action points

- 1) Check whether we need legal disclaimer – there may be standard wording for health websites (i.e. this is information only, does not do instead of a doctor's consultation etc)
- 2) Set up research page if there isn't one already
- 3) Consider setting up live count of number of website hits – not physician count yet as we are only beginning

**LH/JW and Communications team – AGREED AIMS FOR THE YEAR AHEAD**

- 1) Establish website – done
- 2) Establish email lists for all different groups – done
- 3) Design a logo – done
- 4) Set up social media accounts - underway

## Dr Josep Malvehy

**Leader of scientific network**

Core group:

Lionel Larue

Claudia Salgado

JM - Publications and collaboration of research

JM – In future to merge together applications of trials, & international grants. Need to be clear on how to establish proposals. However not ready for this yet

JM – a webpage to make scientific research simple for patients. Video interview of researchers; link to HP clinical trials – simple explanation of science and clinical trials.

JM – PubMed on the website is more for clinicians and physicians but not so useful for patients as its very scientific and medical, so good to have the research digest

**JM and Scientific team – AGREED AIMS FOR THE YEAR AHEAD**

- 1) Write single page for Research part of website, explaining in layman's terms some different scientific concepts, such as what is a clinical trial, what is genetic research, anything JM considers helpful for understanding research into CMN
- 2) Identify from the literature all those groups which have worked in CMN, and mailshot them to join up if they wish. Could also consider other appropriate groups such as the ESPCR list? Scientists who join up can then be asked to write 3 lines on their research into CMN

#### **4. First NI conference 12<sup>th</sup> September 2018, Paris**

MV – states there is an expectation of research updates and talks at this conference because this is what used to happen at the Naevus Outreach conferences. VK reported that this is not detailed anywhere in the conference information. It is definitely the aim

in the longer term, but we would need a bigger meeting, longer time, more funding. VK to provide JW with content for an email to all those that have registered detailing what will be included.

- a. Aims  
Bring together all interested parties from patient support groups, doctors, psychologists, scientists and communications experts to exchange information on what NI is and what its aims are to achieve
- b. Venue  
Paris, linked with the 27<sup>th</sup> EADV Congress Meeting. This reduces costs and means we have more access to speakers and delegates.
- c. Timings  
We have a 4 hour slot allocated to the NI talks free of charge.
- d. Structure  
Originally was two parallel sessions, different audiences, however will be very small conference this time, and only one large room available  
1hr of just leadership team  
1hr of core team meetings (can all meet in different parts of same large room)  
½ hour for each team leader – presentation, plus invited speaker appropriate to their team  
1.5hrs of interactive Q&A session – since this meeting was organised there has been letter from EADV saying 4 hours is maximum. May be possible still to have this interactive session for an hour and to move the leadership meeting to straight after the conference in a different place
- e. Invitations – to all on email lists  
Email directing them to the website to register
- f. Advertising  
Conference Advertisement – Promo flier to send out each month – JW & communications team to facilitate this
- g. Money  
The leadership team and core teams will be funded to attend where necessary (VK, JM already attending EADV)

## 5. Meeting dates for 2019

MV - can we not take conference out of Europe to make it really International. VK stated definitely we are keen to be international, but from practical perspective that it would keep costs low if we were to link it to a relevant meeting, like ESPD this year, EADV 2019. We could consider linking it to AAD Meeting in 2020.

JM – be good to offer the facility to live stream talks (Zoom?) – taking onto consideration the time differences in countries be good to open the conference and reach a wider audience.

JW & Communications team to investigate the options.

VK - concern with live streaming is the use of any clinical photos, so we cannot have them in the presentations, however otherwise excellent idea and should be possible to do without photos. Alternative to live streaming would be to record it and make

available to members, or alternatively to put up all slides other than clinical pictures on website (definitely possible)

12<sup>th</sup> September next meeting

March next leadership meeting

9-13<sup>th</sup> October 2019 EADV in Madrid – if pre-conference meeting again would be 9<sup>th</sup> October