

# Naevus International Core Team Meeting Minutes

Tuesday 11<sup>th</sup> September 2018, 6.30-7.30pm

Chez Audit-CPA, Paris

## **Attendees:**

Veronica Kinsler, Jodi Whitehouse, Marjolein van Kessel, Beatrice de Reviers, Yasmin Khakoo, Harper Price, Lionel Larue

## **Welcome**

VK thanked BR for hosting the meeting and preparing food for team.

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

**1.1** VK explained Naevus International is just starting off.

**1.2** VK explained we are starting very small – little money – but have great people who can offer a lot.

**1.3** VK explained the power of working together rather than separately.

**1.4** VK explained that all the different groups play an important role – equal partnership.

**1.5** VK explained we need to be strategic – focus first on making networks, so that when it comes to the treatment on CMN, etc, we will be ready! We are going to make networks. Secondly, we will then disseminate existing and later new information (including translations) to our networks.

**1.6** VK explained we must all try and keep the big picture – share information we already know with all countries. Invest in these aims and then everything else will follow.

**1.7** VK explained we must keep it multi -disciplinary – unique that we can work together.

**1.8** A question was asked about patient education documents – VK explained we cannot really tackle specific education documents as each country works differently, and we are not here to tell people what to do, but rather to share the information that already exists.

### **2. Aims of the year ahead, including update on progress since June 2018 in achieving aims**

**2.1** VK suggested all minutes need to go onto the website

**2.2** HP finding it difficult to meet with the core team

**2.3** VK asked Jodi to liaise with web designer to check why some of the NI emails are going to people's spam folders

**2.4** HP asked JW to send original NI joining invitation email to her

**2.5** VK suggested that YK joined the clinicians' core team, supporting HP, as she has a novel angle as a neurologist and the expertise will be very helpful. HP was happy for YK to join her team.

**2.6** VK explained new EU GDPR regulations, so we are not able to give patient or parent or patient group advice on email about individuals with CMN, whether named or not, but we are able to disseminate general information, directing people to website.

**2.7** VK explained we must use the website to share information, it will become the hub of all up to date information.

**2.8** VK suggested adding to the website the list of physicians / clinicians who are members of NI. This would have to be done with their permission (optional) when they sign up). We would not be ratifying the qualifications or in any way endorsing the clinicians on the list, merely displaying that they are members. This at least gives an indication of who is interested in which country.

**2.9** VK said we should aim to have the leaflet translated into 10 main languages.

**2.10** HP explained that our responsibility is to disseminate up to date information to doctors , via NI, and also that doctors can contact other doctors about individual cases if they want specific information on particular cases.

**2.11** VK explained that patients can give their local doctor contact details of the medical experts listed on the website. This way the doctors will be discussing patient cases between them, rather than the patient being the go-between.

**2.12** VK wants to know what people want from Naevus International after we have established the networks. A starting point is to ask all groups to complete an online survey which has been designed by VK.

**2.13** LL wondered if we can have a donate button on the website. This needs to be considered.

**2.14** LL said we need to find funding to help develop NI.

**2.15** JW explained the next phase to the website development, including a research section, support resources section, to have the website translated.

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

**3.1** VK said the first Naevus International conference will set the tone of what we are trying to achieve as an organisation.

**3.2** VK thanked the speakers for preparing their talks.

### **4. Collection of outcome data/feedback to assess progress**

**4.1** VK talked through the feedback survey which conference attendees will complete at the conference.

**4.2** MK asked if the survey can be shared beyond the conference attendees. VK wants to encourage as many people as possible to complete the survey. Can be circulated as widely as possible.

### **5. Plan for conference Sept 2019 – content, structure, ideas**

**5.1** VK explained the survey will give us an indication on what people would like to see happen at the 2019 conference.

**5.2** Discussion about best set up for conference, as regards who will be speaking, who will be in the audience, and whether there should be separate clinicians/scientists/patient group sessions, or combined. VK explained that to impart information to the doctors properly, the presenters need to be able to use proper medical language and terminology, which is not easy for scientists or patient groups to understand. Similarly, when talking to scientists, the scientific terminology is not the best format for many doctors, or for patient groups. Proper communication to different groups is achieved by

targeting the talks to the right audience. This is not to say that the data presented will be different. But with a different audience you need a different method of delivery to achieve proper communication. In addition, there was evidence from the Marseille CMN meeting that patient group members in the audience were very upset by some of the medical data presented. This is highly likely to be due to the method of delivery of information in a talk given to other doctors. BR and HP and YK and LL and JW agree with VK points in this matter. VK made clear that there will also be plenary sessions for all groups together, and there will be plenty of opportunity for all the different groups to feed back to the leader team via their representatives. MK worried that the patient groups will feel excluded somehow in the conference. VK not certain how this idea has come about but is definitely not the idea behind the NI conferences.

**5.3** MK suggested there is a mix of all... clinician sessions, patient sessions, mixed sessions.

**5.4** LL suggested the patients should have access to the talks following the conference. Talk pdfs from the first conference to be put on the website.

**5.5** MK explained patients are fearful that their voices won't be heard. VK said that MK is the person to reassure the patients what the overall aims of NI are, including the fact that it is genuinely multidisciplinary, and also to bring their opinions back into the leader team.

## **6. Meeting dates for 2019**

**6.1** MK suggested the next meeting to take place at the Global Skin Conference, connected to World Congress of Dermatology. The conference is taking place in Milan in 10<sup>th</sup> – 15th June.

**6.2** It was agreed that we will give 2 weeks for the survey to be completed and then decide on content of the 2019 conference.

## **7. AOB**

**7.1** VK asked the group if we should consider developing a Fundraising Team and who might lead it.