

Dear Patient Support Group Leaders and interested members,

This newsletter will update you on the activities of Naevus Global. It's the first written (news)letter after the General Assembly June 6th 2017.

Marjolein

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New initiative for Naevus Global

by Veronica Kinsler and Marjolein van Kessel

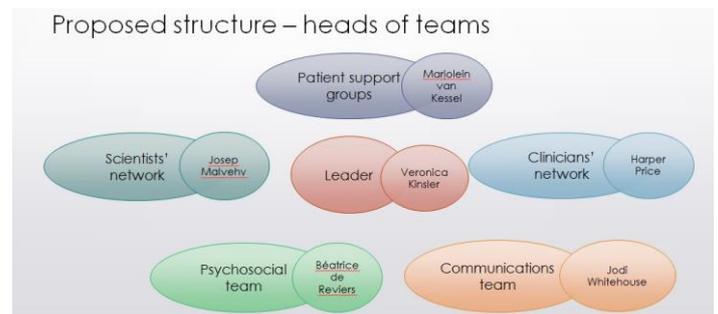
Veronica Kinsler has proposed a new collaboration to have improved access to, and dissemination of, information across and between groups of professionals, patients and families. The new organization will be named Naevus International and get a new logo presenting a new start. It will take over the Naevus Global website and Facebook page.

I'm looking for people interested in joining the 'patient support groups team'. If you would like to be involved it would be good if your interests are reading, listening and talking about medical literature, research and guidelines on CMN. In the collaboration I hope we can improve the healthcare for CMN by making visible where to find expertise

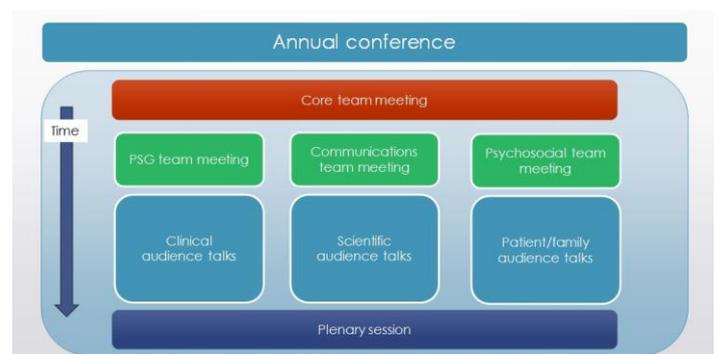
worldwide, achieving consensus on treatments and providing newest information on research to the public. By joining the team you would need to be able to join conferences online and meeting each other at least once a year in Europe. All patient support group leaders would be included in the broader patient support group team.

If you would like to be actively involved in the 'patient support groups'-core team, please send an e-mail to

mvankessel@naevusglobal.org or marjoleinvankessel@gmail.com.



Structure meetings



Nevus Global Day or international CMN awareness day

by Yoav Gaon (Israel)

There's an initiative to organize an Nevus Global Day or international CMN awareness day.

The goals would be:

1. Raise awareness to children and families to GCN & NCM
2. Show case all the countries organizations dealing with support to our cause and offer them to donate money for research and organization activities.

Key Players are:

1. Nevus Outreach USA
2. Caring Matters UK
3. Children of light Israel

But other organizations may join too.

Operation:

- Build a website called GlobalNevusDay like the model of <https://worldcpday.org/> or use our own websites to promote the day.
- Have designed a branded logo for the Nevus Global Day. All associations can use the logo to promote the awareness day, by posting it on their social media platforms and on their websites. We can also ask our own members to upload the logo as their profile image for the day / week.
- Create a global social media campaign showing people and families with and without nevus putting dots, taking pictures of themselves and sharing the message of 'spot on the dot'!

If you would like to be involved, please send an e-mail to Yoav Gaon <yoav@yoocantech.com>

Denver 2017 – International Pigment Cell Conference

by Mark Beckwith

Pigment Cell Societies from around the world joined together for the 2017 International Pigment Cell Conference in Denver in the USA from August 26-30. For the first time, the topic of Congenital Melanocytic Nevi was given a full day program.

Dr. Veronica Kinsler was chosen to chair the session. She invited world expert speakers to present on a variety of topics to bring the assembly up to date on the state of the art for CMN-related cares and cures. Among the presentations:

Dr. Josep Malvehy – Barcelona, Spain
International registry of GCMN and ongoing collaborative research

Prof. Pierre Vabre – Dijon, France
Psychological support initiatives for CMN

Mrs. Jodi Whitehouse – Liverpool, UK
Changing the image of CMN

Dr. Lionel Larue - Paris, France
Murine models of pigmentary disorders

Dr. Elizabeth Patton - Edinburgh, UK
Zebrafish models of pigmentary disorders

Dr. Satyamaanasa Polubothu - London, UK

Phenotypic and genotypic factors governing the natural history of CMN lightening and implications for treatment

It was a good opportunity for those in attendance to connect with the experts and learn what was happening in the various parts of the world-wide body of work - the international registry, current thinking about psycho-social effects of CMN, and current work on animal models.

Representatives from a number of patient associations including Naevus Global were present, allowing for interaction between the realms of physicians, researchers, and patients. For more information about the talks above, more details are available from Naevus Global.

**Global Skin conference, Geneva,
September 14th -17th**

by Marjolein van Kessel

GRIDD: Global Research on the Impact of Dermatological Diseases

The IADPO (Global Skin) was founded two years ago in Canada. The International Alliance of Dermatology Patient Organizations (IADPO) is a unique global alliance, committed to improving the lives of skin patients worldwide. Global Skin has asked us to work together in the GRIDD project, together with other skin disorders on a global level, to research the impact of dermatological diseases.

In dermatology, to date, no research has been conducted on a global level to study the

impact of dermatological diseases. For a very small amount of specific conditions, some country-specific impact studies have been done. There is virtually no research that has been driven by the patients themselves, in ANY disease area, where they themselves create the questions that will elicit responses that will answer the question of the true impact.

GRIDD is unique because patients come up with the questions they will answer themselves. Once the research is done we'll collectively own the data. Data can be used for advocacy. The media will have facts to tie to your patient stories. It can boost fundraising.

Other presentations given at the conference:

The common experience of Dermatological Diseases

Gitte Aabo, CEO Leo Pharma.

WHO targets: The critical importance of the patient voice

Dr. Cherian Varghese, coordinator
Management of NCDs

The power of the patient voice

Dr. Chris Bundy, University of Cardiff

Plenary session Healthcare Value assessments – injecting the patient voice
different successful organizations

Scientific Advances in Dermatological care

Dr. Jan Dutz professor, department of dermatology and skin science

Plenary session shared objectives – benefits and challenges of collaboration between patient organizations and pharma



Leo Pharma, Galderma, Novartis, Celgene

For more information on the presentations, a full report is available from Naevus Global.

Visiting the Italian nevus gathering

by Marjolein van Kessel

September 8th and 9th I attended the Italian conference gathering. The children's activity organized by Dr. Rosalba Semeraro (psychologist) and Sharon Rosati (student psychologist) used the themes earth, fire, water and air/wind for activities. Dr. Rosalba Semeraro is a psychologist working as a volunteer for Naevus Italia. She is doing research in a project named ICONE (IMage COrps NEvus, 'body image nevus'). Her study is about the quality of life of someone with CMN depending on the child's self-esteem, anxiety, optimism, and empathy. She also looks at the influence of parents, which can be both positive and negative. The study is unique in the world and results will be interesting to share. Dr. Stefano Latorre is a plastic surgeon reaching out to work with Naevus Global. He gave a presentation.

On the picture left to right: Francesca Funaro (communications), Marjolein, Corrado Giani (vice president), Luca Pate (president and founder) of Naevus Italia.



New connections for Naevus Global:

At the Global Skin conference I met two people willing to be a contact person for people with CMN in western Africa and Northern Africa.

Western Africa:



Ogo Maduwesi, founder of Outer Shell Africa, an organization to support different skin conditions. Their mission is social wellness and social inclusion for Sub-Saharan Africans living with skin conditions and visible differences outershellafrica@gmail.com or contact@outershellafrica.org www.outershellafrica.org

Northern Africa:



Myriam Lamine is president of the vitiligo association of Tunisia. She would like to be a contact person for other skin conditions in Tunisia (her country), Algeria and Morocco.

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