

VIPOC Committee

VIPOC Conference 2020 Bangalore India

Supporters/Sponsors

UNKNOWN VITILIGO : SKIN DISEASE AUTOIMUNE WITH SEVERE BURDEN

Children, women, men; 100 million people suffer from vitiligo around the world.

Vitiligo is not just an aesthetic disease but it is also of a systemic autoimmune nature with severe burden.

Appearance of depigmented skin areas is often indicative of other important comorbidities for the patient: thyroid dysfunctions (30% of cases), alopecia areata, gastric diseases, rheumatism, etc.).

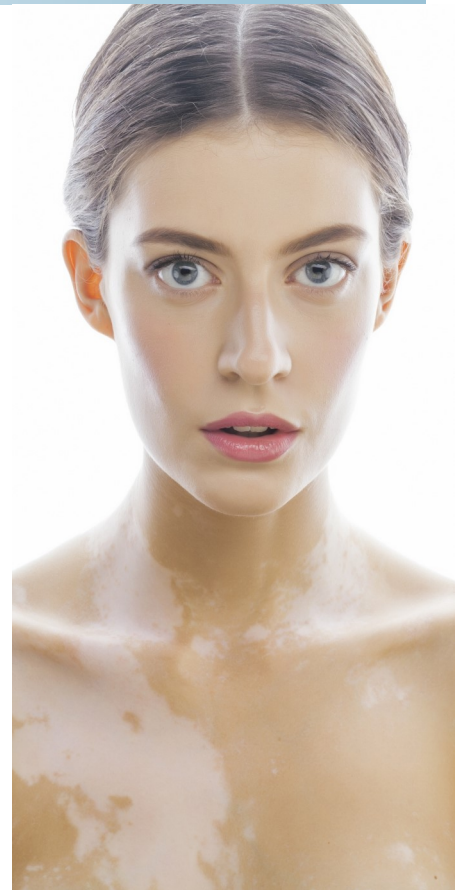
Throughout their lives, vitiligo patients need a drug or several treatments but also dermatological products for sensitive skin care, skin depigmented protection (hydration, sun protection, make-up products, etc.).

VIPOC COMMITTEE—VIPOC CONFERENCE 2020 TWO OPPORTUNITIES TO MEASURE THE MARKET

Pharmaceutical and cosmetic laboratories are invited to become partners by providing moral and financial supports which will be used for the operational organisation and events of VIPOC Committee (headquarter in Paris) and for VIPOC Conference 2020 which will take place in Bangalore India on December 2020.

Vitiligo International Patient Organisations Committee is the worldwide alliance of vitiligo patient organizations build in 2018 during the first Vitiligo International Patient Organizations Conference and now official NGO based in Paris.

Vitiligo International Patient Organisations Conference 2020 : 3rd to 6th December 2020 more than 25 nations are forecasted to take part to this conference. Patient leaders and scientists will be sharing views, expertises, projects, etc. during 3 days with researchers, dermatologists, pharma industries representatives. VIPOC Conference 2020 will take place in Bangalore - India.



Sommaire

- Unknow disease
- To measure the market
- Core funding levels
- Conference 2020 supports
- VIPOC 2018 success
- What is all VIPOC now ?
 - Advocacy
 - Research
 - Support and best practices
 - Organization Mgt
- Steering committee



To support better patients in 2020
To advocate for better care and cure
To fight against discriminations

VIPOC Conference 2020 Agenda (provisional)

Thursday evening December 3rd 2020 : Opening session and diner with all delegates

“VIPOC today and tomorrow, vitiligo patient leaders towards equality for cure and care” Jean-Marie Meurant - France, President of Vitiligo International Patient Organizations Committee

Friday December 4th 2020 : Vitiligo Patient leaders day

- ♦ **Regional patient advocacy today, perspectives and projects for a Worldwide view**
 - Europe Georg Pliszewski - Germany
 - North America Pat Rossy - USA
 - Africa Gaone Tlhong– South Africa
 - Asia Maya Tulpule - India
 - South America (tbd)
- ♦ **How clinical researches are launched and run ? What are the frame for collaboration between pharma industries and patient organizations ?** Oana Bernard - France
- ♦ **How and why to inform and advocate with regulators and health authorities about burden and impacts ? Roles and duties of national patient organizations and VIPOC in cure reimbursement negotiation process**
Jean -Marie Meurant – France
- ♦ **Burden of vitiligo disease, impacts and comorbidities studies today ? How to build a study and to argue ?**
Dr Viktoria Eleftheriadou – UK, Dr Richard Huggins – USA
- ♦ **Action plan 2021-2025** focus groups per region and worldwide

Saturday December 5th 2020 : Vitiligo researchers/scientists and Vitiligo patient leaders day

- ♦ **Pathogenesis of Vitiligo** Dr Mauro Picardo - Italy
- ♦ **Clinical aspects of vitiligo** Pr Thierry Passeron - France
- ♦ **Medical treatment, new drugs** Dr John Harris - USA
- ♦ **Surgical treatments** Dr Davinder Prasad - India
- ♦ **Quality of life, burden of Vitiligo** Pr Khaleed Ezzedine - France
- ♦ **Genetics and Vitiligo** Pr Richard Spritz - USA
- ♦ **Worldwide Vitiligo guidelines** Pr Julien Seneschal - France
- ♦ **How to interact to get more funds for research ? New ways to collaborate** group discussion

Sunday December 6th 2020 closing session

⇒ Annual General Meeting and 2025 Perspectives



Worldwide, Leaders at the heart of actions to help patients in 2020

VIPOC 2020 Financial support for :

Core funding for

- Networks with scientific societies, researchers groups, dermatologist federations, etc.
- Advocacy in regions (Americas, Asia, Europe) and worldwide (WHO, UN, ILDS, etc.)
- Contact and projects with patient centric pharma industries
- Information and competencies development for patient leaders on clinical trials, guidelines, new research, impacts and burden studies, etc.
- Staff activities, development of communication tools (website, newsletter)

Conference 2020 funding for

- 3 days conference organization and contribution to transport and accommodation for VIPOC 2020 delegates,
- Scientist, researchers, speakers venues
- Video conferencing system for larger audience, etc.

VIPOC 2018 : the success

More than 50 patient leaders and scientists coming from the 5 continents

On April 5 and 6 2018, the first Vitiligo International Patient Organizations Conference took place in Paris during 2 days.

This first VIPOC Conference was a very big success by bringing more than 50 Patient leaders and researchers together as well Pharma representatives interested by this autoimmune/ genetic/ inflammatory disease.

3 key outputs :

- Building a global vitiligo patient organizations alliance/committee with a steering committee named during the conference
- International guidelines for vitiligo to be issued with patient and GP versions



© Krista Monteiro, NL



Investing in the future of an unknown disease

In center of vitiligo today and tomorrow

VIPOC Committee And VIPOC Conference 2020

VIPOC Committee : a worldwide patient organizations to support vitiligo advocacy and information center. VIPOC headquarter is located in Paris (France)

VIPOC Conference 2020 : Three days of international talks, strategic thinking, medical and scientific information for leaders of patient organizations, for researchers involved and for pharmaceutical and cosmetic laboratories looking for vitiligo, linked comorbidities (thyroid deficiencies, rheumatoid, stomach, etc.), autoimmune variations and psychological and depression aspects. VIPOC 2020 will take place in Bangalore India 3 to 6 Decembrer 2020

Sponsors areas and levels for companies to support

Core Funding VIPOC Committee

Platinum your logo in communication tools (website, newsletters), the opportunity to participate to our training, conferences and videos for vitiligo leaders : 30.000 Euros

Gold your logo in communication tools (newsletters), the opportunity to participate to our training and videos for vitiligo leaders : 25.000 Euros

Silver your logo in communication tools (newsletters), the opportunity to participate to our training for vitiligo leaders : 20.000 Euros

Bronze includes your logo in communication tools (newsletter) : 15.000 Euros

Conference funding is available for Core funding partners

VIPOC Conference 2020 funding

Platinum includes participation to conference day for two employees of your company, sponsors a thematic dinners, your logo in communication tools, a booth and your documentation in the conference spaces, the opportunity to organize a one-hour focus group with vitiligo leaders : 20.000 Euros

Gold includes participation to conference day for two employees of your company, your logo in communication tools, a booth and your documentation in the conference spaces : 15.000 Euros

Silver includes participation to conference day for one employees of your company, your logo in communication tools and your documentation in the conference spaces : 10.000 Euros

Bronze includes your logo in conference tools : 5.000 Euros





WHAT'S ALL THIS ABOUT A NEW PATIENT ORGANISATION, WHAT IS VIPOC ? COMMITTEE AND CONFERENCE

VIPOC's Steering Committee

During the first Vitiligo International Patient Organizations Conference held in Paris, all patient participants agreed about the need for a global and strong vitiligo advocacy organization and an international support network for local vitiligo patient organizations.

To build this strong patient organization, VIPOC' attendees gave the mandate to launch the process to an enlarged VIPOC steering committee:

Ms Jackie GARDNER (USA)

Ms Myriam LAMINE (Tunisia)

Mme Nicole MAQUIGNON (France)

Mr Adrian MAR (Australia)

Mr Jean-Marie MEURANT (France)

Mr Paul MONTEIRO (Netherlands)

Ms Patricia ROSSY (USA)

Ms Gaone TLHONG (South Africa)

Ms Maya TULPUL (India)

In addition, Maxine Whitton MBE (UK) with her long experience about vitiligo advocacy and patient organizations accepted the role of Adviser.

Since VIPOC's days in Paris, the steering committee made several decisions through videoconferences and mail exchanges.

VIPOC : the name

The steering committee decided to call the organization: VIPOC - Vitiligo International Patient Organizations Committee – and to also use the acronym for the next conference by changing the last word 'Committee' to 'Conference'.

This allows the organisation to also use the website and address - www.vipoc.org.

The acronym has become known through the 2018 conference.

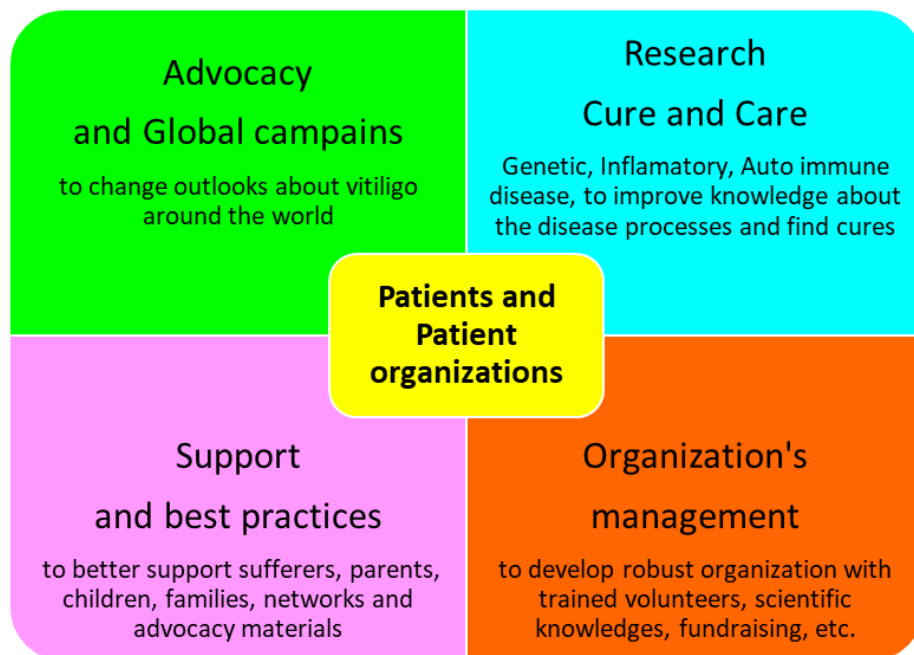
VIPOC Vitiligo International Patient Organizations Committee is now alive!

Vitiligo International
Patient Organizations
Committee



VIPOC's areas of actions

VIPOC'S attendees and steering committee agreed to have broad action areas to develop vitiligo awareness through the new international patient organization.



In more details

Advocacy/Global campaign

- To reach out to Vitiligo people, Media, Health Policy Makers, Researchers and Pharma industry.
- To get treatments under insurance cover by changing the category of Vitiligo from Cosmetic disease to Non-Communicable disease.
- To inform and advocate about high vitiligo disease burden and impacts to health authorities in order to get high level of care reimbursements
- To support new global guidelines for dermatologists
- To create better awareness and empathy amongst Dermatologists and their scientific societies around the world.
- To inform students and general practitioner with communication tool about Vitiligo and impacts
- To reach out to people who do not have Vitiligo to change their outlook on Vitiligo.

Research

- Help and fund for Genetic and Immunology Research in respective continents.
- Work closely with pharma industries in drug research processes and with researchers, particularly in trial design where appropriate, as well as trial participation
- Increase of patient voice in development of new drugs
- Patient involvement in research, helping to identify appropriate research needs and also being involved in research design, e.g. psychological interventions.

Support and best practices

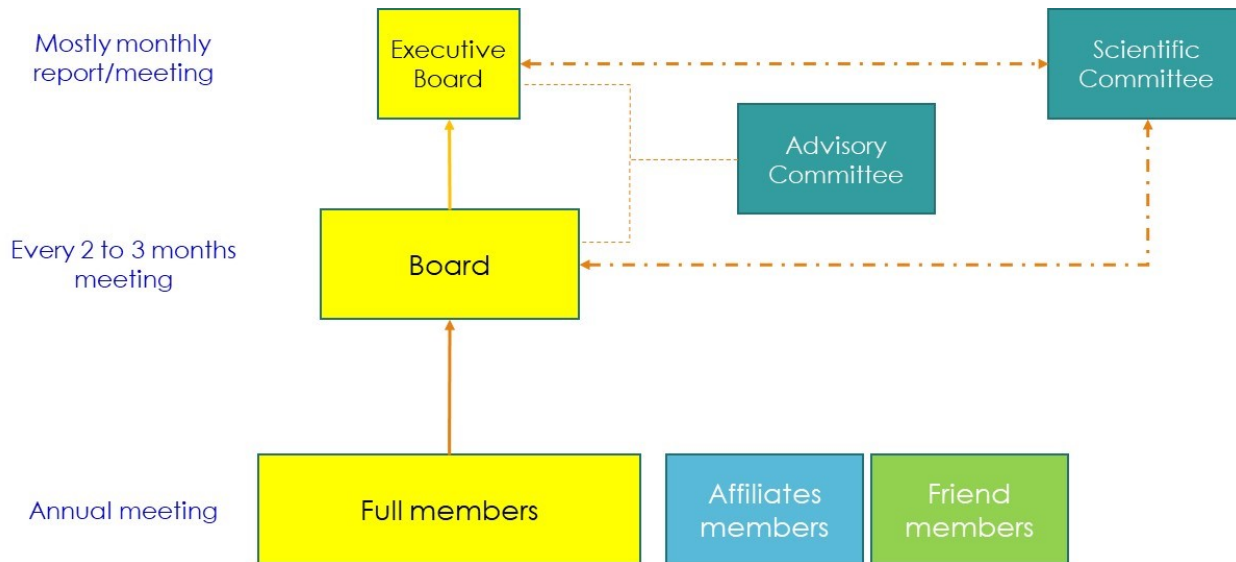
- Psychological, Sexual and professional impact studies.
- Parenting and proper guidance to children.
- Support for vitiligo patient families

Organization's management

- Advocacy to health and regulator authorities
- Advice on how to run support groups successfully.
- Fundraising techniques.
- Volunteer training programs.
-

VIPOC : Non profit organization officially registered

The aim is to have a non-profit organization managed by a majority of patient leaders with a Scientific Committee and an Advisory Committee.



3 categories inclusion by decision of the « Member commission » (composed with 3 board's members)

- Full members (voting member)
 - Official organizations (sub group of official organization)
 - Vitiligo oriented
 - Non profit
 - Patient led (majority of the board)
- Affiliates members (non voting member)
 - Individual patients or non declared organizations
- Friend members (non voting member)
 - Individual, organizations, companies, and societies funding VIPOC and/or supporting vitiligo patients

VIPOC headquarter in Paris

The steering committee agreed to have the headquarters of Vitiligo International Patient Organizations based in Europe and specifically in Paris, France.

VIPOC is an official “association” ngo based in Paris and ruled bu Law of July 1st of July. Official declaration at Préfecture de Police de Paris and publication in Journal Officiel de la République Française on November 2019.

Direction de la Police Générale
Service des associations
30 rue des Archives
75003 Paris

Le numéro 0751254736
est à reporter dans toute
correspondance

Résumé de Déclaration de CREATION
de l'association n° 0751254736

Vous le soumettez au préfet de police en 11 copies de l'original.
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Le préfet de police

Compte rendu de la réunion du 24 novembre 2019
Président : M. le Préfet de Police
Président : M. le Préfet de Police
Président : M. le Préfet de Police

Paris 15e, le 20 novembre 2019

Pour le Préfet de Police et par délégation
Pour le Directeur de l'Information
Légale et Administrative
Bertrand MUNCH

Sandrine ROULAND - G1

151^e année - N°48

Samedi 30 novembre 2019

JOURNAL OFFICIEL
DE LA RÉPUBLIQUE FRANÇAISE

Associations et fondations d'entrepreneurs

DIRECTION DE L'INFORMATION
LÉGALE ET ADMINISTRATIVE
26, rue Desaix, 75727 PARIS CEDEX 15

www.journal-officiel.gouv.fr

Associations
Associations syndicales
de propriétaires

Fondations d'entreprise
Fonds de dotation
Fondations partenariales

Annonce n° 1475
75 - Paris
ASSOCIATIONS
Créations

Déclaration à la préfecture de police
COMITE INTERNATIONAL DES ORGANISATIONS DE PATIENTS ATTEINTS DE VITILIGO - VITILIGO
INTERNATIONAL PATIENT ORGANIZATIONS COMMITTEE (VIPOC)
Objet : faire reconnaître la réalité du vitiligo et des malades qui y sont associés, réunir les organisations des
malades du vitiligo pour mieux faire entendre la voix de leurs malades, les malades et les personnes ou sociétés impliquées dans le vitiligo et la recherche, défendre les malades du vitiligo, leurs
regroupements, les intérêts présents et futurs des personnes atteintes du vitiligo ou malades associées, ainsi que
ceux de leurs familles, soutenir et représenter les regroupements de malades du vitiligo au sein de toutes instances
nationales, régionales et internationales, mener des actions d'information, de soutien, de défense, de recherche, de
communication, de représentation globale, de réflexions éthiques, etc., sur le vitiligo et ses conséquences, informer
et mener des études, des recherches sur les impacts du vitiligo et des maladies associées à travers le monde,
soutenir toutes les recherches en prenant les contacts nécessaires avec les médecins, les équipes médicales, les
chercheurs, les laboratoires, les sociétés scientifiques et savantes intéressées par le vitiligo, les comités de l'association
ou indirectement, contribuer à atteindre les objectifs de vitiligo international patient organizations committee VIPOC,
élaborer des actions de sensibilisation du public en général.
Siège social : 11, rue de Clichy, 75009 Paris.
Date de la déclaration : 24 novembre 2019.

Le Directeur de l'information légale et administrative : Bertrand MUNCH

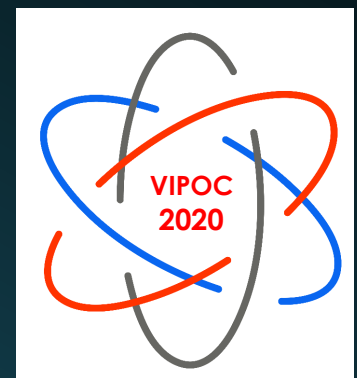
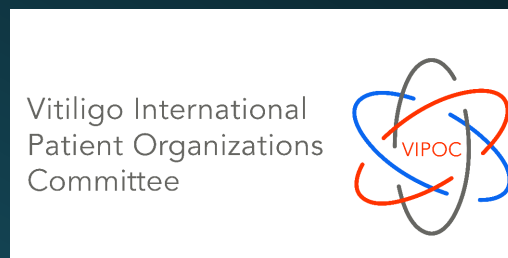
Take part to VIPOC's journey !

For better cure and care for vitiligo patients around the world

Support now

VIPOC committee
&
VIPOC Conference 2020

From one conference to global committee and VIPOC 2020



Our growing voice

Vitis International Patient Organizations Committee

Head Office : 11 rue de Clichy 75009 Paris France

www.vipoc.org

Contact

President Jean-Marie Meurant : president@vipoc.org - +33 (0)6 0806 0649

General Secretary Nicolle Maquignon : general-secretary@vipoc.org

Treasurer Georg Pliszewski : treasurer@vipoc.org

Association ruled by law of July 1st 1901, registered on November 24th 2019 at Préfecture de Police de Paris and publication in Journal Officiel de la République Française November 30th 2020

General and social Interest Association