ASSOCIATION FRANÇAISE
DU VITILIGO
WWW.AFVITILIGO.COM

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Vitiligo International Patient Organizations Conference

VIPOC
2018

VIPOC Newsletter N°4

PARIS 2018 APRIL 5 – 6

VIPOC NL n°4

Summary

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VIPOC 2018 : A START

THINK GLOBAL, TO BETTER ACT LOCAL

Detailed conference program inside

Vitiligo leaders : the rising voice

VIPOC's promotion enables me to enter into contact with more than 300 FB vitiligo support groups.

All over the world people with vitiligo have the same concerns and are asking themselves the same questions over and over.

Vitiligo impact everyone on many levels: physically, emotionally, socially and economically, and make vitiligo a very difficult disease to bear.

Thereis lack of information; some people don't know that vitiligo can be treated and are looking for miracles drugs and treatments.

Vitiligo Facebook groups leaders are very enthusiastic about VICOP 2018 new challenges, and agree that we need to be more linked internationally, work not only on national bases to raise vitiligo awareness around the world.

Ana ArenaAFV board member, volunteer

your VIPOC International Contact

(continued page 2)

VIPOC fees : only 270 Euros when pre-registration and payment before 20 February 2018 ! (page 15)

PATIENT COMMENTS AROUND THE WORLD

(continued from page 1)

Feedbacks below speak from themselves and argue that all vitiligo leaders around the world have to work together in unity if we expect to see changes.

"This initiative is worthy of admiration for all the leaders and patients of vitiligo, in my case I carry with honor the two attributes.

We strive, we work tirelessly in our communities with the aim of providing support to patients and family members.

It is a reality that we have to globalize this support, if we carry out this type of meeting we have more opportunities than our claims are heard internationally,....I recognize and support the organizers of this First Conference for leaders of groups of patients with vitiligo, which I congratulate from now on and I wish you success."

"keep me informed, I would like to participate more actively"

"I do not understand; this disease affects so many people, and there is no definite explanation of the cause, nor a treatment for vitiligo, I've been to several dermatologists, some even prescribe me some topical medication, which are usually expensive, and since the lesions are extensive, they don't know how the people with vitiligo suffer!"

"Let us clear the myths and doubts about Vitiligo. A person with Vitiligo can get married and live a normal life like any other person"

"I think it's excellent because there are so many people waiting for a cure and they do not do anything for that purpose, and there are people who are only taking advantage of giving false hope where there are none and taking money and cheating with medicine that does not work, it's good and I congratulate you if you do that globally to see if we really get the cure because there are many people who need it, and if we all talk and support each other we will achieve it"

Ana Arena Report, AFV board member, volunteer

your VIPOC International Contact

ana.arena@afvitiligo.com

LEADERS COMMENTS AROUND THE WORLD

As a founder of Beyond Vitiligo and a lady living with vitiligo.

It’s about time we come together as a nation to stand up for those who haven’t find their voices as they are dealing with the psychological impact that’s associated with vitiligo.

We need to continue fighting the stigma global and we really need to know the really causes of vitiligo as we are working together with the scientists in finding a cure.

We shouldn’t overlook the psychological impacts that vitiligo has on a person, let’s make it our duty to educate people about vitiligo and hoping to make things easier for the next generations.

It takes a community to do better than an individual. I am looking forward to 2018 VIPOC conference and excited to learn more about the condition from the medical perspectives and latest on the condition.

Gaone Tlhong
Founder of Beyondvitiligo
Johannesburg, South Africa
www.beyondvitiligo.org
www.Facebook.com/BeyondvitiligoSA
Twitter: @Beyondvitiligo

28 years ago when first diagnosed with vitiligo, I was told that vitiligo treatments were ineffective, dangerous, and not recommended. 10 years later after a death in my family, my vitiligo began spreading rapidly.

I researched and found that there were treatments that worked, but I still could not find a local dermatologist willing to prescribe them. Even when I provided peer reviewed research articles, I was denied.

The doctor told me that if my appearance bothered me, to not look in a mirror.

My vitiligo continued to spread until I finally found a doctor who understood and cared.

As I began treating my vitiligo, my soul also began to heal. I then had a mission to help others.

I have been the Executive Director of VSI for 10 years. As a patient advocate, I have communicated with hundreds, if not thousands of vitiligo patients experiencing the same struggles and problems that I had nearly 30 years ago. Each time I hear from a patient who’s been told there are no treatments, or that vitiligo won’t hurt them, it rekindles my desire to make sure the voice of the patient is heard.

Jackie Gardner
Executive Director
Lynchburg, Virginia USA
Vitiligo Support International (VSI) www.vitiligosupport.org/

LEADERS COMMENTS AROUND THE WORLD

I am President of Vitiligo.nl (former LVVP) for about nine years.

My aim (together with the board) is to make this association an organisation with business rules: a real strategy to make vitiligo visible for the medical world, but also to make it more visible for all the people with (and without) vitiligo in Holland, who are hidden, because of shame. We think that it is very important that our members are involved in a lot of things.
Especially in research activities.

Vitiligo patients are looking at the patientsorganisation Vitiligo.nl, because they are waiting for the answer, for the solution, for solving their problem, at least information/ feed back of the research results.

Also the psychosocial aspects (health related quality of life) of vitiligo are not always taken seriously by the medical world. Important, doctors should more think; I'm not only for the cure, but also for the care!

International cooperation: Vitiligo International Patients Organizations Conference (VIPOC) wil be a success if we can build a bridge between the world of researchers and the world of vitiligopatients, sharing information/ results, etc.

What I always say: Create your own shine moments: Live, enjoy and just do……even with vitiligo!

Paul Monteiro
President of Vitiligo.nl
Amsterdam Netherlands
www.vitiligo.nl

I am Dr Adrian Mar the current President of the Vitiligo Association of Australia (VAA).

The VAA was formed in 2010 to address the need of vitiligo sufferers, their carers and clinicians, and has representatives from all of the main states of Australia.

Dermatologist based in Melbourne, I am one of the founders of the Vitiligo Clinic at the Skin & Cancer Foundation and an Associate Professor at Monash University.

As VAA President, I hopes to connect those with vitiligo and an interest in this condition through support groups, online forums and meetings such as VIPOC.

I am particular excited and honoured to be involved with the inaugural VIPOC event.

With its diverse and changing population and geographical position within Asia, Australians understand the need to co-operate with their neighbours and across cultures in order to bring about the best outcomes.

VIPOC promises to bring such a spirit of collaboration for the benefit of vitiligo sufferers around the world.

Dr Adrian Mar
President of Vitiligo Association of Australia
Riverwood Australia
www.vitiligo.org.au

LEADERS COMMENTS AROUND THE WORLD

Vitiligo is noncontageous, not life threatening disorder which changes the looks there by carrying lot of social stigma in Indian subcontinent.

It is devastating as far as looks are concerned.

There is no 100 % curative treatment found yet , though lot of research is going on .

I feel the best way to handle Vitiligo is to accept it , take best treatment and should have best family support .

Shweta Association from Pune ,India is working tirelessly to improve quality of life of these people for last 17 years.

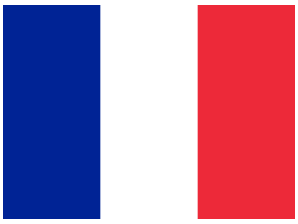
I appeal earnestly to all the people having Vitiligo to love themselves and their body.

We should feel ourself fortunate that there is no physical disability .

Let's come together and work towards betterment of Vitiligo people all over the world.

Maya Tulpule
President of Shweta India
Pune India
www.shweta.org

SCIENTISTS COMMENTS AROUND THE WORLD



International cooperation in vitiligo

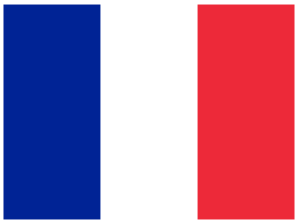
Vitiligo is a disease with a worldwide distribution, and its impact on populations with a large range of skin color has motivated the creation of specialized clinics or more rarely research labs in all five continents.

Cooperation has started at a regional level, for example in Europe, the Vitiligo European Task Force was created in 2003, with regular annual meetings at EADV and/or ESPCR (respectively European Academy of DermatoVenereology and European Society for Pigment Cell Research).

Since 2010, international junction has been possible at Vitiligo Global Issues Consensus Conferences (VGICC) held at international meetings like IPCC (International Pigment Cell Conferences Bordeaux 2011, Singapore 2014) or World Congresses of Dermatology (Seoul 2011, Vancouver 2015).

More recently "vitiligo only" research meeting witness the coming of age of the field at the international level (Rome Vitiligo International Symposium 2016). International cooperation has allowed several advances in definitions, scoring, data gathering, therapeutic guidelines, and outcome measure research. Building on such an international cooperation is important at a critical time when new drugs reach clinical development.

Pr Alain Taïeb
Bordeaux France
Chair Department of Dermatology and Pediatric Dermatology University Hospital, Director of Dermatology Rare Diseases Reference Department,
Director of Dermatology Research Department Inserm 1035



Comorbidities with vitiligo : Shared histological relationships underlying generalized vitiligo and some auto-immune diseases ?

Epidemiological findings reported that generalized vitiligo involves genetic susceptibility loci shared with other auto-immune diseases. Nevertheless the initiating process has not well been elucidated.

Further study is needed to identify the initiating factors inducing generalized vitiligo and auto-immune disorders. So the purpose of the investigation of our multicenter group was to perform a comparative and a concomitant histological study in vitiligo patients suffering from systemic or dermatological auto-immune disorders. For each vitiligo patient a skin biopsy material was provided by Dermatology departments,and biopsies from their non dermatological pathologies were obtained from Endocrine surgery, Gastro- Enterology, and Pathology departments.

Vitiligo offers many benefits as a model for the study of auto-immunity in that it could be used to identify the contributing roles of various factors implicated in the initiation of auto-immune disease.

Yvon Gauthier MD
Bordeaux France
Researcher, Ancient Head of Pigmentary Disorders out-patient Clinic Department of Dermatology Hopital Saint André

SCIENTISTS COMMENTS AROUND THE WORLD

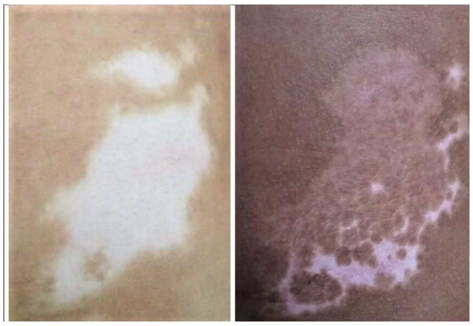
Transplantation technique by microneedling

Since the first description of a transplantation technique of basal cell layer suspension (Gauthier et al. 1992), several modified methods were proposed for re-pigmenting the skin of selected vitiligo patients.

All these invasive methods need a previous destruction of the depigmented epidermis. So a simple technique, minimally invasive could be desirable. Microneedling delivering systems using dermaroller or dermastamp could offer a minimally invasive and painless method for transepidermally delivering isolated cells.

The objective of our study**,** in 12 selected cases of vitiligo, was to develop a new, simple and non expensive method which could be easily used by dermatologists.

The trial was registered at NIH clinical trials NCT02962180. Finally, after 6 months, a good re-pigmentation > 75% was obtained in 8 cases. The wound healing was very rapid from 1 to 3 days, the repigmentation started earlier in 15 days with no side effects.



Baseline After 3 months

*Ref.: Benzekri L. ,Gauthier Y. Pigment Cell Melanoma Res. 2017 Sept;30 (5):493-497

Laila Benzekri MD, PhD

Rabat Morrocco

Professor at Mohammed V Souissi University, Dermatology Department University Hospital Ibn Sina

New hope for vitiligo

As a dermatologist involved in skin research, I use my skills to develop clinical and research programs to better understand mechanisms leading to vitiligo. Vitiligo is now considered as a chronic inflammatory skin disease.

Indeed, our main focus is to decipher the role of the exaggerated immune response in the disease. Our research led to new discoveries and new targets for potential future therapies. This was done with the help of all our patients seen in our vitiligo clinic in Bordeaux.

Today, we are in a new era for treatments dedicated to vitiligo. Research projects are growing and many pharmaceutical companies are now looking for testing new molecules in this disease.

However, getting new treatments in medicine takes time and it is our role to always communicate on our programs and research projects for patients' organizations.

Research on vitiligo needs time, support and funding with a the aim to improve the understanding of the disease for a better care.

Professor Julien Seneschal M.D, Ph.D
Bordeaux France
Department of Dermatology and Pediatric Dermatology
National Reference Center for Rare Skin Diseases INSERM U1035 ATIP-AVENIR Immunodermatology University of Bordeaux
www.dermatobordeaux.fr www.**u1035**-inserm.fr/

SCIENTISTS COMMENTS AROUND THE WORLD

Altered cross-talk between dermal and epidermal components

Despite significant studies contributed to a greater knowledge of vitiligo, understanding its pathogenesis is still a challenge.

Vitiligo is characterized by the disappearance of functional melanocytes, and multiple mechanisms might contribute to this loss, nevertheless a growing amount of evidence in recent years argues for intrinsic metabolic defects in melanocytes leading to a condition of stress induced premature senescence-like and impairment of mitochondrial function, leading to high basal intracellular ROS production, have been proposed as a pivotal player in the onset of the disease.

Such metabolic impairment is not restricted to melanocytes but also extended to fibroblasts indicating the existence of altered cross-talk between dermal and epidermal components which may affect melanocyte functionality even in the apparently normal skin of vitiligo patients and supporting the presence of a stress-mediated senescence phenotype extended to the entire skin

Recently, an altered pattern of distribution of the adhesion molecule E-cadherin has been described in clinically normal pigmented skin, indicating the presence of melanocyte adhesiveness impairment that, in presence of stress, may facilitate and contribute to melanocyte loss. Collectively these results point to the involvement of the entire skin in vitiligo, even in normal appearing skin, showing the presence also in the dermal compartment of cells with a premature senescence phenotype.

These cells, producing skin aging-associated secreted proteins, can in turn affect melanocyte functionality favoring their loss. Focusing on normal-appearing skin may allow us to recognize the occurrence of cellular phenomena before the clinically manifested onset of the disease and possibly restrict the spread of the lesions.

Mauro Picardo, MD
Director of Cutaneous Physiopathology and Metabolomic
Centre San Gallicano Dermatology Institute Sapienza Università di Roma

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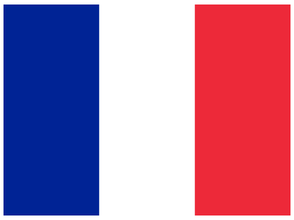
International INitiative For Outcomes for vitiligo (INFO for vitiligo)



In the last years, vitiligo has come to the forefront with advances in the understanding of the physiopathological pathways underlying the disease and several FDA approved drugs are of potential interest in the treatment of vitiligo.

In this perspective the vitiligo scientific community has conducted an international e-Delphi consensus on core outcomes set for vitiligo, led that involved 101 participants from 25 countries worldwide including patients, clinicians, representatives of regulatory authorities and journal editors. Three outcomes were identified as essential: repigmentation, cessation of spread and side effects.

Regulatory authorities such as the food and drug administration of the European Medical Agency are now asking for more input from patients in reporting outcomes of treatment, i.e. is the treatment successful from the patient point of view?, and we are currently on the way of developing such outcomes with the help of patients.

We have organized in 2017 three workshops with patients and are currently on the way for publishing the results of these workshops. Research on outcomes is essential for setting clinical trials and encouraging the drug industry to conduct clinical trials. For this purpose we have created an international group named **International INitiative For Outcomes for vitiligo (INFO for vitiligo)** under the auspices of the Cochrane community.

Our ambition is to set-up every two years an international meeting for outcomes in vitiligo that will involve regulatory authorities, researchers, clinicians and most importantly patients.

Khaled Ezzedine, PhD
Créteil France
Professor of Dermatolog — AP-HP University Hospital Créteil

VIPOC 2018

AIM

We, together, will build an amazing Vitiligo future during 2 days

The first Vitiligo International Patient Organizations Conference will be a unique opportunity to meet and share experiences and actions of defense and support across the 5 continents.

The various testimonies gathered and our daily experiences demonstrate the imperative needs to work together to truly be able :

- To defend the interests of the patients and their families,
- To help in cure and in care the children, women and men affected by this disease and comorbidities associated to vitiligo,
- To support researchers in all vitiligo fields in order to increase the resources devoted to fundamental and clinical research,
- To support and bring together researchers and leaders of vitiligo in order to disseminate scientific and verified information in a digital world where patients are lost and lose their health and livelihoods,
- To advocate, to defend constantly and everywhere to change the global view on vitiligo and on affected people.

But alone I am alone and together with all of us I am and You are strong.

The rules of “health game” are global even if we have to act locally with vitiligo patients in very different cultures and traditions.

To fully fulfill our role as organizations of vitiligo patients and as leaders, we must retain and further develop our vitiligo organizations in the closest to the field of patients by country but also to equip us with a transversal organization at international level to succeed.

As patient leader, I ask to be part of the journey and to have my voice joined to all patient leaders to define the way and the manner to organize and being represented. By such a global patient organization we will be patient focus.
It is therefore necessary to build together a global vitiligo voice capable of acting around the world in a concerted manner to lobby globally and regionally, to build advocacy strategies, to share information and communications, to offer for free news, photos and images for our newsletters and communication tools, to be beside and with the researchers for funding, to argue with health regulators and insurances for medicament and psychological/camouflage refunds in relation to what is done in the region, etc.

All vitiligo patient leaders and vitiligo organizations are invited to take part of this tremendous target to decide together on what to build and what we want to have for vitiligo patient improvement.

In two years from now, vitiligo patient situations must have to change with our supports.
We all have part of the solution.

Jean-Marie Meurant
Paris France
VIPOC coordinator, President of Association Française du Vitiligo

VIPOC
LEADERS DAY
5 APRIL 2018

Starting at 8.30 am	
Introduction : VIPOC steering committee members (10 min)	
Introduction : VIPOC perspectives and leaders expectations (10 min)	Jean-Marie Meurant
Introduction : VIPOC Final program presentation (10 min)	Steering Committee members
Vitiligo questionnaire answers (organizations, leaders, etc.) and debate (30 mn)	Steering Committee members
Get to know each other better per region ? (Africa, Americas, Asia, Arabic countries, Europe) - What are our practices, our strengths and weaknessess ? How can we help each other ? (60 min + 50 min)	Steering Committee members Working groups, plenary session, debate, discussion on best practices
 Break (11.20—11.40)	
« Patient organizations : new roles in Health Technology Assesment processes. How to better represent and advocate for vitiligo patients ?» (20 min)	Matteo Scarabelli - European Rare Diseases Network Eurordis (Eurordis)
Personnal perspectives : What surprises me ? What is a challenge for me? What do I need to be trained about ? What changes to my organization are needed ? (15min)	Plenary and group session
Table group synthesis- Debate - Q&A (35 min)	Matteo Scarabelli (Eurordis) and Christine Janus (IADPO)
3 crucial subjects for vitiligo leaders to focus on (10 min)	Post-it session and prioritization
 Lunch time 13.00 to 14.00	
Sharing 6 Vitiligo Best Practices : advocacy, psychological support, make-up, patient empowerment, fundraising, children (6 BP/5 min each = 30 min)	Volunteers Patient Representatives (tbd)
Debate - Q&A (30 min)	Steering committee members
Patient advocacy : How do we build a strong voice and robust organizations ? (20 min) Debate - Q&A (20 min)	Christine Janus - International Alliance of Dermatology Patient Organizations
Break (15.40—16.00)	
What focus is needed in the coming years to establish a Worldwide Vitiligo Voice? Discussion and proposals (60 min)	3 working groups
Plenary session feed back (3 groups x10 mn) Q&A (30 min)	Debate and proposals
The most important objectives and outcomes to be achieved in terms of the organization and governance of a « Worldwide Vitiligo Voice »	Post-it session, prioritization and vote
Conclusion and Focus on	Jean-Marie Meurant
End at 7.00 *pm* ; Dinner « under construction »	

VIPOC
RESEARCH DAY
6 APRIL 2018

Starting at 8.30 am	Speakers and participants
Introduction: patients' perspectives and expectations (10 min)	Jean-Marie Meurant
Vitiligo: a challenge for scientists and physicians (10 min)	Mauro Picardo
Normal skin pigmentation and its regeneration plus Q&A (40 min)	Thierry Passeron and Hee Young Kang
Vitiligo: clinical subsets and predisposing factors plus Q&A (40 min)	Alain Taïeb and Jung Min Bae
Break (10.40—10.55)	
Recent advances in understanding vitiligo and the vitiligo pharma pipeline plus Q&A (40 min)	Julien Seneschal and Thierry Passeron
Current useful treatments for vitiligo (medical & surgical) plus Q&A (40 min)	Marcel Bekkenk and Steven Thng
Phototherapy for vitiligo, including unmet needs (40 min) plus Q&A	Henry Lim and Flora Xiang
Lunch time 12.55 to 13.35	 Time for lunch.
Epidemiology, comorbidities, disease burden: arguments for a better communication with health authorities plus Q&A (40 min)	Khaled Ezzedine and Julien Seneschal
Vitiligo disease severity and extent: perception from the patients' and the dermatologists' points of view plus Q&A (40 min) »	Nanja van Geel and Laila Benzekri
Break (15.00—15.15)	
How to improve interactions between the esearch community and patient advocacy group o leverage funds for research, clinical trials, etc. Working groups session 1 (45 min)	Scientists, reaerchers and patient representatives
How to communicate with health authorities to better patient care ? Working groups session 2 (45 min)	Scientists, reaerchers and patient representatives
Plenary session, working group feedback : Action plans	Steering Committee members
Lessons from my personal experience : Vitiligo yesterday, to day, and tomorrow plus Q&A (30 min)	Yvon Gauthier and Mauro Picardo
Closing session, summary and roadmap (3 major objectives to achieve in 1 , 3 and 5 years (15 min)	Alain Taïeb and Jean-Marie Meurant
End at 7.00 pm	
Dinner « under construction »	

VIPOC 2018 program version previsionnal 2

Scientists attending VIPOC 2018 for a global view and direct contacts

Alain Taïeb PhD

Chair Department of Dermatology and Pediatric Dermatology University Hospital Bordeaux,

Director of Dermatology Rare Diseases Reference Department,

Director of Dermatology Research Department Inserm 1035 (Imaging working group)

France

Confirmed

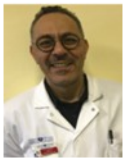
Mauro Picardo, MD

Director of Cutaneous Physiopathology and Metabolomic

Centre San Gallicano Dermatology Institute Sapienza Università di Roma (Imaging working group)

Italy

Confirmed



Khaled Ezzedine, PhD

Professor of Dermatology

AP-HP University Hospital Créteil

France

Confirmed

Marcel Bekkenk MD, PhD

Dept Dermatology / Netherlands Institute for Pigment Disorders Academic Medical Centre University of Amsterdam (Imaging working group)

Netherlands

Confirmed

Laila Benzekri MD, PhD

Professor at Mohammed V Souissi University, Dermatology Department University Hospital Ibn Sina Rabat

Morocco

Confirmed

Yvon Gauthier MD

Researcher, Ancient Head of Pigmentary Disorders out-patient Clinic Department of Dermatology Hopital Saint André Bordeaux

France

Confirmed

Indermeet Kohli

(Physicist, deputized by Iltefat Hamzavi)

Department of Dermatology

Henry Ford Hospital Detroit

USA

Confirmed

Scientists attending VIPOC 2018 for a global view and direct contacts

Henry W. Lim, MD,
Chair Emeritus Department of Dermatology Henry Ford Hospital Detroit, MI,
President American Academy of Dermatology

USA
Confirmed

Jung Min Bae, MD, PhD
Assistant Professor
Department of Dermatology, St. Vincent's Hospital
College of Medicine, The Catholic University of Korea (Imaging working

Korea
Confirmed

Thierry Passeron, PhD
Professor of Dermatology
University Hospital Nice (Imaging working group)

France
Confirmed

Julien Seneschal MD, PhD
Prof. Head of ATIP-AVENIR team (Immuno-dermatology INSERM 1035
Dpt of dermatology and pediatric dermatology Bordeaux University
Hospital (Imaging working group)

France
Confirmed

Steven Thng
Executive Director, Skin Research Institute of Singapore,
Senior Consultant, Head, Pigment Clinic, National Skin Centre, National University of Singapore (Imaging working group)

Singapore
Confirmed

Nanja van Geel, MD, PhD
Department of dermatology
Ghent University Hospital (Imaging working group)

Belgium
Confirmed

Hee Young Kang, MD, PhD
Professor Department of Dermatology,
Ajou University School of Medicine, Suwon (Imaging working group)

Korea
Confirmed

Flora Xiang
Vice Chair, Department of Dermatology
Huashan Hospital Shanghai Medical College (Imaging working group)

Shanghai
Confirmed

VIPOC AFV

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NOVARTIS

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GENÉVRIER

Pierre Fabre
Dermo-Cosmétique

VETF
Vitiligo European Task Force

Christian Diehl, est un pharmacologue qui a toujours été passionné par la physiologie de la peau, et depuis 1980 il a décidé de se concentrer sur sa passion. Il a créé successivement plusieurs compagnies avec succès, toutes dans le même domaine, tout en étant Consultant de plusieurs multinationales pharmaceutiques. Aujourd´hui il consacre plus de 35 ans d´expertise professionnelle en exclusivité à **LSI**.

LSI est une entreprise pharmaceutique orientée vers la dermatologie, la chirurgie plastique et la médecine esthétique. LSI est concentrée sur le développement de cosmétiques et nutraceutiques destinés au traitement et à la prévention des maladies de la peau et du vieillissement cutané. Notre objectif est d´offrir aux professionnels de la santé des alternatives innovantes, à l´efficacité prouvée et sûres pour leurs prescriptions.

Récemment, le Dr Christian Diehl a consacré son expertise et ses connaissances pour trouver une crème innovatrice traitant le problème du Vitiligo avec des résultats cliniques remarquables.

PRE-REGISTER NOW!

Pre-registration

To participate in VIPOC 2018, you need to pre register at www.vipoc.org https://www.eventbrite.fr/e/vipoc-2018-pre-registration-registration-38574908590

Within a few days you will receive a link for the final registration and payment.

Limited places available

VIPOC fees : only 270 Euros when pre-registration and payment before 20 February 2018 !

Dear Vitiligo leader,

Having pre-registered for VIPOC 2018 and it is now time to complete your final step for VIPOC registration.

Your financial contribution : 250 Euros + 20 € admin fee (Total 270 Euros payment before 20 February 2018, after this date 600 €) for VIPOC 2018 conference includes :

- 2 days VIPOC 2018 conference (5 and 6 April 2018)
- 3 nights : Wednesday 4 April 2018 2.00 pm to Saturday 7 April 2018 10.00 am), 3 breakfast and 2 lunch meals at CISP Ravel
- Free invitation to buffet and 25th Anniversary celebration of the Association Française du Vitiligo (from 10.30am to 5.00 pm) at Espace du Centenaire Paris with English translation provided.

To register and pay, you will already have recieved or will soon recieve a mail with a link to pay a Paypal account or with your credit card on a safe and secure system. Do not hesitate to contact us http://www.vipoc.org/en/contact-page/

How to get funds for your travel costs?

Using VIPOC brochures as argument of proof, to ask for financial support to the pharma companies could also be a way.

VIPOC newsletter, publishing the list of the scientists already registred at VIPOC, can also help convince your contributor.

We are working hard to build a travel grant to enable a largest number of participants to attend VIPOC 2018.

We are still waiting for additionnal positive answers from sponsors. In any case, it will cover only some of the costs. After VIPOC financial closure in May 2018, we'll ask you to send us your request and travel invoices to proceed at a prospective financial support.

How to seek funds from our vitiligo communities ?

There are many ways to get funding to help you to participate at VIPOC : a donation from your vitiligo community is one of them. Pointing out your committment through your interest in VIPOC and your advocacy work, could also help raise funds for the vitiligo cause.

Like you as a vitiligo leader, those in the community will be generous, but people will want to know their money will be used to benefit others..
Examples of areas where ongoing :funding is needed include :

- Improving the quality of life for those with vitiligo, especially children,
- Developing new areas of research to find a cure;
- Combatting discrimination and stigmatization.

Your participation at VIPOC can be in the purpose of a fundraising camapin. Some of you may already have thought support from a generous donor. Small donations from a large number of people work as well : appealing to thousands for a few dollars may be better than getting a big amount from one person only.
Vitiligo patients are a large and involved community. Some of them will be ready to help you to participate in VIPOC in April 2018 and trusting that you to speak on their behalf, at an international forum.

To make it easier, you could use Facebook's tools to collect donations and enable your supporters to fundraise your nonprofit project. On several national or international websites, you will find existing tools to help you and your community to gather more supporters.

Try and give it a go !

What to do if you want to come before and/or after VIPOC to visit Paris and surrounds ?

VIPOC registration will include 3 nights—*Wednesday 4 April afternoon to Saturday morning 7 April 2018.*

If you want to come earlier or stay longer, go to CISP Ravel reservation page to book additional rooms.

Book soon to be sure of getting good prices. Accomodation may fill quickly !

Where is VIPOC located ? How do I get there from Paris international airport ?

VIPOPC will be located at CISP Ravel (International stay center) ,

6 avenue Maurice Ravel, 75012 PARIS (Paris south east downtown)

If your arrival is at Roissy - Charles de Gaulle airport ,

- After customs , go to the underground train station AEROPORT CDG 2 TGV (between terminal 2C and 2D) (Circle red on the airport map)
- Buy a train ticket at an electronic counter at the train station entrance (around 12.50 Euros per ticket to downtown Paris)

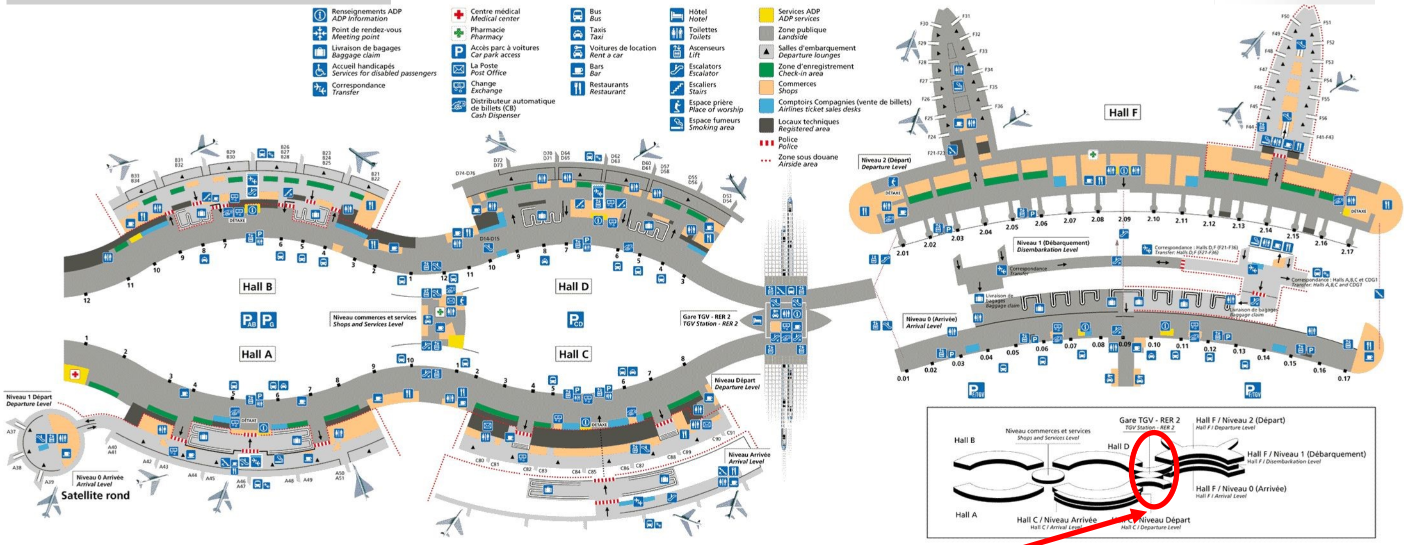
RER B

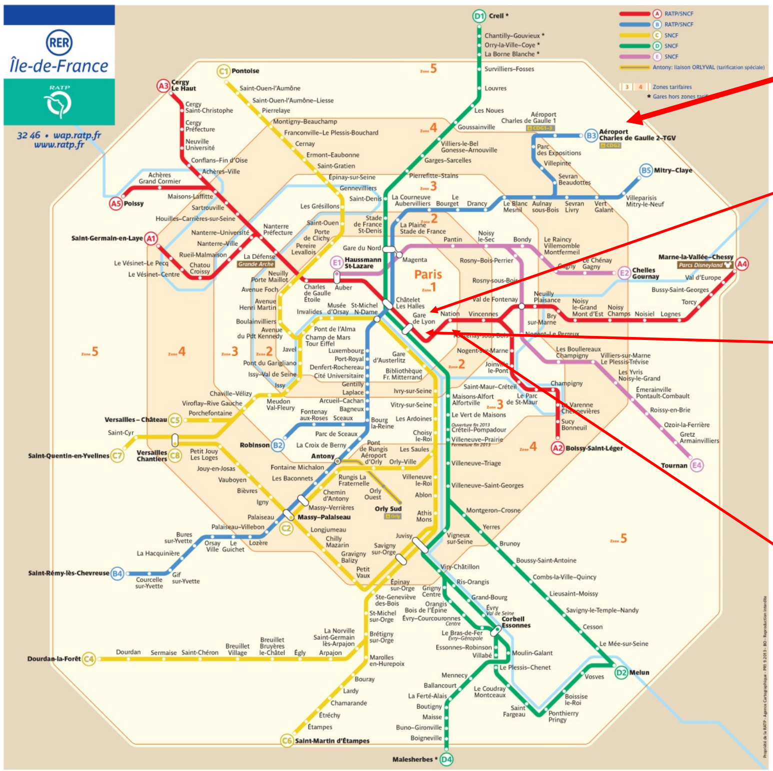
Take the RER B train heading to « Gare de Saint-Rémy-Lès-Chevreuse » and disembark at « Cité Universitaire » station to transfer to the T3a line

T 3a

Take the train heading to « Porte de Vincennes » and disembark at « Alexandra David-Neel » station then

It is the an approximatively 5 mon walk to CISP Maurice Ravel





Imaging CitizenM Gare de Lyon

AFV 25th Anniversary

VIPOC 2018 CISP Ravel

VIPOC 2018 AND PARIS ONLY FOR YOU

VIPOC 2018 conference, Imaging scientific group meeting, and the 25th Anniversary of Association Française du Vitiligo are all conveniently located within the same area of downtown Paris

All major touristic sites can be reached by metro or RER within minutes .

Arc de Triomphe

Champs Elysées

Louvre musée

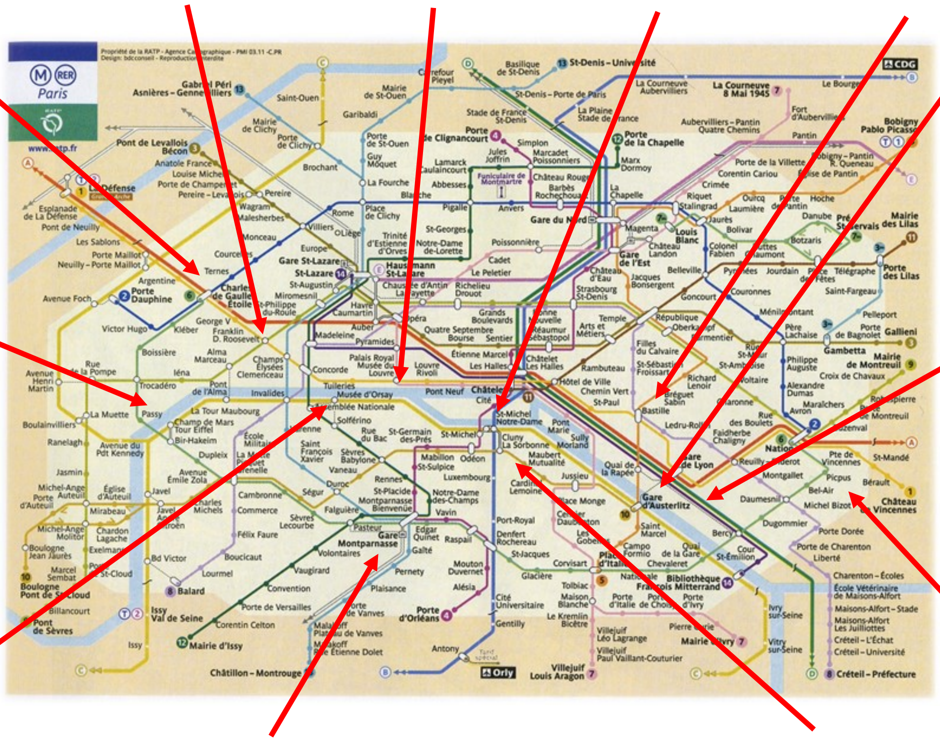
Notre Dame

La Bastille

Imaging CitizenM Gare de Lyon

Trocadéro

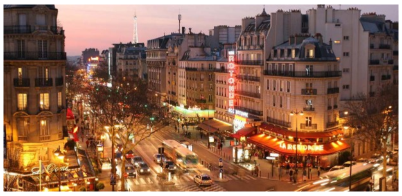
Tour Eiffel



AFV 25th Anniversary

VIPOC 2018 CISP Ravel

Musée d’Orsay



Montparnasse

Quartier Latin

La Sorbonne

VIPOC 2018 (meeting and rooms) : CISP Ravel 6 avenue Maurice Ravel 75012 PARIS

Imaging scientific group meeting CitizenM Gare de Lyon 8 Rue van Gogh 75012 Paris

25th Anniversary of Association Française du Vitiligo Espace du Centenaire RATP 189 rue de Bercy 75012 Paris

All venues are located in a close proximity to one another in downtown Paris

VIPOC 2018

APRIL, 5&6 2018

VIPOC 2018 will be held in the Centre International de Séjour de Paris Individual, CISP Maurice Ravel Paris (www.cisp.fr). Participants will be able to book their accommodation in same site of conference. Conference cost per individual : 250 Euros + 20 Euros administrative fees = 270 € (included 2 days of conference, 2 lunch meals during the conference, 3 nights accommodation Wednesday afternoon to Saturday morning in individual rooms with all basic comfort at CISP Maurice Ravel including 3 breakfast meals). You are invited for free to attend the 25th anniversary of the Association Française du Vitiligo on Saturday 7 April 2018 beginning at 10.30 am English translation is provided. Fees payment before 20 February 2018 for 270 € (after 600 €).

Financial assistance may be available to participants, particularly for travelling costs, dependent on funding support received for VIPOC 2018. The organization of VIPOC 2018 is overseen by two international committees: **The VIPOC 2018 Steering Committee** is composed of leaders of various vitiligo patient organizations from across the world, ensuring a diversity of topics, cultural perspectives and experience (in alphabetical order) :

Ms Jackie Gardner (USA) www.vitiligosupport.org
Ms Myriam Lamine (Tunisia) www.atvitiligo.org
Mr Adrian Mar (Australia) www.vitiligo.org.au
Mr Jean-Marie Meurant (France) wwwafvitiligo.com
Mr Paul Monteiro (Netherlands) www.vitiligo.nl
Ms Maya Tulpule (India) www.myshweta.org
Ms Gaone Tlhong (South Africa) www.beyondvitiligo.org
South America patient organization (in progress)

Coordination is provided by Association Française du Vitiligo 11 rue de Clichy 75009 Paris France www.afvitiligo.com
Jean-Marie Meurant jean-marie.meurant@afvitiligo.com

The **VIPOC 2018 Scientific Committee** : The panel of international experts in vitiligo research is currently being assembled and includes : Dr Mauro Picardo (Italy) and Prof Alain Taïeb (France) (see p 13 –14)

VIPOC 2018: A COMMITMENT TO THE FUTURE THROUGH FINANCIAL SUPPORT

Pharmaceutical and cosmetic companies are invited to become partners of VIPOC 2018 by providing financial support to:

- Sponsor VIPOC conference participants through a travel and accommodation allowance
- Provide official sponsorship of the Vitiligo Dinner held on Thursday 5th April 2018, with the topics «How can links between vitiligo patient organizations and the pharma industry be strengthened?» and «Vitiligo in children»
- Provide official sponsorship of the Vitiligo Dinner held on Friday 6th April 2018, with the topics « The future of global healthcare» and « One skin, one vitiligo»
- Celebration and spaces of the partners during VIPOC 2018 conference (optionnal Celebration of 25th Anniversary of French Vitiligo Association April 7th)

For more information : Jean-Marie Meurant jean-marie.meurant@afvitiligo.com
Cell phone : +33(0) 6 0806 0649 Association Française du Vitiligo, ruled by law 1901, July 1st,
Registered at Préfecture de Police de Paris Head office : 11 rue de Clichy 75009 Paris—courrier@afvitiligo.com

ASSOCIATION FRANÇAISE DU VITILIGO
WWW.AFVITILIGO.COM

Building together

Together to success

Success is not the key to happiness. Happiness is the key to success.

If you like what you do, you will succeed.

Dr Albert Schweitzer (1875 - 1965)