VIPOC Newsletter March 2025

Hello Advocates

2025 is off to a powerful start for VIPOC!

The first quarter has been nothing short of extraordinary, from game-changing advocacy efforts to global collaborations that are putting vitiligo on the map like never before. With momentum from our successful Cairo conference, we're charging ahead with fresh initiatives, bold campaigns, and stronger-than-ever connections within the vitiligo community.

A major milestone? We officially launched The Vitiligo White Paper! This groundbreaking report is set to redefine vitiligo advocacy, providing crucial insights and data to drive global change (The Vitiligo White Paper - VIPOC).

Keep reading for exclusive highlights, success stories, and what's coming next!

Message from the Acting President

I'm honored to connect with you as we continue advancing vitiligo advocacy worldwide. From launching The Vitiligo White Paper to the impactful work of our member organizations, we are making real progress in awareness, support, and policy change.

The success of the VIPOC conference in Cairo, the extraordinary involvement of the patient leaders present, and the close ties with researchers, scientists, and dermatologists who tirelessly work on vitiligo are living testaments to VIPOC's actions since its creation in 2019.
We are nearly 45 vitiligo patient organizations from 30 countries worldwide working to

support and inform patients as closely as possible.
On Saturday, April 19, 2025, we will hold the VIPOC Annual General Meeting online, an opportunity to review the awareness-raising and advocacy efforts carried out since 2023 and VIPOC's current strong financial position, thanks to rigorous management.
It will also be an opportunity to renew the members of the Board of Directors for the next three years.
Each patient organization that is a member of VIPOC can nominate a representative to be elected and thus directly participate in the development of VIPOC and all its efforts to defend vitiligo patients.
Registered VIPOC members will receive the invitation and links to register for the online Annual General Meeting and to apply for board membership positions during the week.
If you are not yet a member of VIPOC, please feel free to join and join the great story of VIPOC and global vitiligo advocacy through this link https://www.vipoc.org/membership-form/

Your dedication drives this movement, and together, we will keep amplifying patient voices and pushing for better care. Thank you for being part of this journey, let's keep moving forward!

Warmly,
Jean-Marie Meurant, Acting President, VIPOC

Important Date: VIPOC Annual General Meeting 2025

Saturday, March 19th, 2025, online meeting (expected duration 90 min) starts at

GB **London (United Kingdom)** → 14:00 (GMT)
FR **Paris (France)** → 15:00 (GMT+1)
US **New York (United States)** → 10:00 (EDT)
CA **Vancouver (Canada)** → 07:00 (PDT)
US **Los Angeles (United States)** → 07:00 (PDT)
AU **Melbourne (Australia)** → 01:00 (March 20) (AEDT)
IN **Delhi (India)** → 19:30 (IST)
ZA **Cape Town (South Africa)** → 16:00 (SAST)
EG **Cairo (Egypt)** → 16:00 (EET)

(see above Message from the Acting President)

Successful VIPOC Fourth Conference

The 4th Vitiligo International Patient Organizations Conference (VIPOC) in Cairo, Egypt, marked a historic milestone as the first VIPOC event held in Africa, uniting 40+ participants from 25 countries in a dynamic celebration of collaboration and progress. This groundbreaking gathering solidified VIPOC's role as a catalyst for global change, blending cutting-edge research with passionate advocacy to redefine the future of vitiligo care.

Key Highlights:

- **Visionary Leadership:** Esteemed experts like Dr. Maya Tulpule, Pr Thierry Passeron, Prof. Dr. Nanja van Geel, and John E. Harris shared transformative insights into treatment breakthroughs and research innovations.
- **Patient Powerhouses:** Advocacy leaders Gaone Matewa and Jean-Marie Meurant spearheaded discussions on grassroots strategies, youth engagement, and equitable access to care.
- **Action-Driven Workshops:** Interactive sessions empowered participants to amplify patient voices in clinical trials, strengthen regional networks, and address mental health challenges.

This conference was a resounding success, blending scientific rigor with patient-centered passion. By fostering dialogue between researchers, clinicians, and advocates, VIPOC Cairo laid the groundwork for tangible advancements, from global registries to mental health support frameworks. The energy was palpable, reflecting a shared commitment to elevating vitiligo care worldwide.

The Future is Bright:

VIPOC Cairo's legacy will ripple globally, inspiring new collaborations and amplifying the voices of those living with vitiligo. Stay tuned for updates on the next chapter in this journey!

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The EU Vitiligo White Paper

The Vitiligo White Paper

Rewriting The Vitiligo Patient Experience: The Vitiligo White Paper

Current challenges and needs in the diagnosis, management and care of vitiligo

VIPOC has achieved a historic milestone with the launch of *The Vitiligo White Paper in Europe*, a groundbreaking initiative addressing critical gaps in the diagnosis, management, and care of vitiligo across Europe. This marks a major step toward improving healthcare policies and strengthening patient support worldwide.

Developed in collaboration with leading scientists and dedicated patient representatives, the White Paper presents key policy recommendations. It highlights challenges such as misdiagnosis due to lesion variability, lack of treatment options, and the significant impact of vitiligo on mental health and quality of life.

On January 15, 2025, this pivotal document was published online and presented at the European Parliament in Brussels. It gained recognition from key policymakers, including Members of the European Parliament, European Commission representatives, and the World Health Organization, reinforcing the urgency of addressing vitiligo care.

Led by Professors Thierry Passeron and Nanja Van Geel, with VIPOC Vice President Jean-Marie Meurant championing patient voices, this achievement reflects a collaborative effort between patient organizations and top dermatologists. The White Paper sets the stage for stronger advocacy, improved medical recognition, and meaningful policy changes for vitiligo patients worldwide.

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Member Community Updates

40 Members

30 Countries

4 Conferences

The Vitiligo International Patient Organization (VIPOC) is unstoppable! Our advocacy and awareness efforts are making waves, pushing vitiligo to the forefront like never before. With 40 powerhouse members from 30 countries, our global footprint keeps expanding. Four groundbreaking conferences down, and we're just getting started! From uniting patient leaders to driving real change, VIPOC is shaping the future of vitiligo advocacy worldwide.

Achievements and Activities

Canada

Vitiligo Voices Canada (VVC) celebrates one year of impact! Since launching in January 2024, VVC has grown to 500+ members, shared 25+ vitiligo stories, launched monthly support calls, and raised awareness through media and landmark light-ups; including the CN Tower and Niagara Falls for World Vitiligo Day. With big plans for 2025, their journey is just getting started! Congratulations Vitiligo Voices Canada!

Africa

Royal Patches Foundation hosted a powerful Rare Disease Day event, bringing together patients, caregivers, medical experts, and advocates. The day featured inspiring panel discussions, heartfelt stories, and moments of joy, highlighting the resilience of the rare disease community. A huge thank you to all who participated, this is just the beginning of the movement for better awareness, policies, and support!

France

The French Vitiligo Association, recently participated in the 2025 edition of pharmagoraplus, the largest gathering of pharmacists in France. Martine Carré, president of the association, and Jean-Marie Meurant, vice president of the French Skin Federation, represented the vitiligo community during this impactful congress. Over two days, they engaged in insightful discussions, delivered conference talks, participated in interviews, and connected with key partners. Their presence at this event highlights the ongoing efforts to raise awareness and foster collaboration for the vitiligo community.

During Dermatology Days in Paris, the French Vitiligo Association showcased advocacy, research, and collaboration, with impactful discussions, presentations, and an immersive experience highlighting vitiligo awareness and support. Over 12,000 dermatologists engaged in vital conversations on improving care, while the Association's booth and international meetings emphasized global collaboration for vitiligo progress

USA

On 7 March 2025, Beautifully Unblemished celebrated the birthday of Tonja Johnson, the founder and heart of Beautifully Unblemished! Her dedication and vision have created a strong, supportive community for vitiligo patients. Join us in celebrating her and wishing her a day filled with joy and appreciation! Happy Birthday, Tonja!

Saint Martin

On February 12, the Vitiligo Educate Inspire Support St. Martin (V.E.I.S.S.) Association visited Collège Mont-des-Accords for an engaging session with four classes of students. The session sparked curiosity and great discussions, and the students will now write essays based on the presentation and their research. Special thanks to Joyce, Lillian, President Jackie, and Founder Gerline Isaac for leading this initiative. The V.E.I.S.S. team is grateful to the school for the opportunity to connect and share their mission, and they look forward to more outreach opportunities.

Latest News

Vitiligo International Patient Organizations Committee

4th VIPOC CONFERENCE
Shaping the future of Vitiligo care

From December 12 to 15, 2024, the 4th edition of the Vitiligo International Patient Organizations Conference (VIPOC) was held in Cairo, Egypt, marking its first-ever gathering on the African...

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Vitiligo International Patient Organizations Committee

Newsletter September 2024

Summary of Newsletter September 2024: Message from President, VIPOC Fourth Conference—Cairo, Member Community Updates, Upcoming Events...

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Vitiligo International Patient Organizations Committee

EADV Amsterdam 25-28
September 2024

During the EADV conference held in Amsterdam from September 25 to 28, 2024, a total of four dedicated VIPOC board members took part in the event*: Paul Monteiro...*

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