# THE GLOBAL ALBINISM ALLIANCE
# 2025 I ANNUAL REPORT

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# ANNUAL OVERVIEW

← Carol, Chair of the GAA, USA

In 2025, the Global Albinism Alliance (GAA) continued to strengthen its role as a global reference point for albinism. Through advocacy, convening and strategic partnerships, the Alliance worked towards a world in which persons with albinism live with dignity, equality and effective access to health and human rights.

For the first time in five years, the GAA held two in-person membership meetings, in Prague and Cape Town, bringing together leaders from more than 50 albinism organisations across all regions.

In January, the virtual *International Scientific Conference on Albinism* (ISCA25) reached record participation and helped advance biomedical research and evidence-based responses to key health challenges.

A major milestone was the *World Health Organization's* inclusion of broad-spectrum sunscreen for persons with albinism on the *Model Lists of Essential Medicines*, following sustained, collaborative advocacy with partners including the *UN Independent Expert on albinism*. Building on this, the GAA co-organised the first *World Forum on Skin Cancer Prevention and Management in Persons with Albinism* in Cape Town, uniting dermatologists, researchers, policy-makers, global health experts and advocates to clarify the burden of disease, identify barriers and outline scalable interventions. These efforts aligned with the theme of International Albinism Awareness Day 2025 *"Demanding our Rights: Protect Our Skin, Preserve Our Lives"* and with the 10th anniversary of the UN mandate on albinism.

At global policy level, the adoption of two World Health Assembly resolutions – *"Skin Diseases as a Global Public Health Priority"* and "Rare Diseases: a Global Health Priority for Equity and Inclusion" – signalled increased commitment to inclusive health agendas relevant to persons with albinism.

Internally, the GAA expanded its team, strengthened digital outreach and supported over 150 member associations and NGOs through capacity-building, resources and collaborative programmes. At the same time, ongoing challenges – including attacks in some regions, persistent stigma and inequalities in education, employment and healthcare – underline the continued need for protection, justice and comprehensive inclusion.

# EDITORIAL

## Antoine Gliksohn
EXECUTIVE DIRECTOR

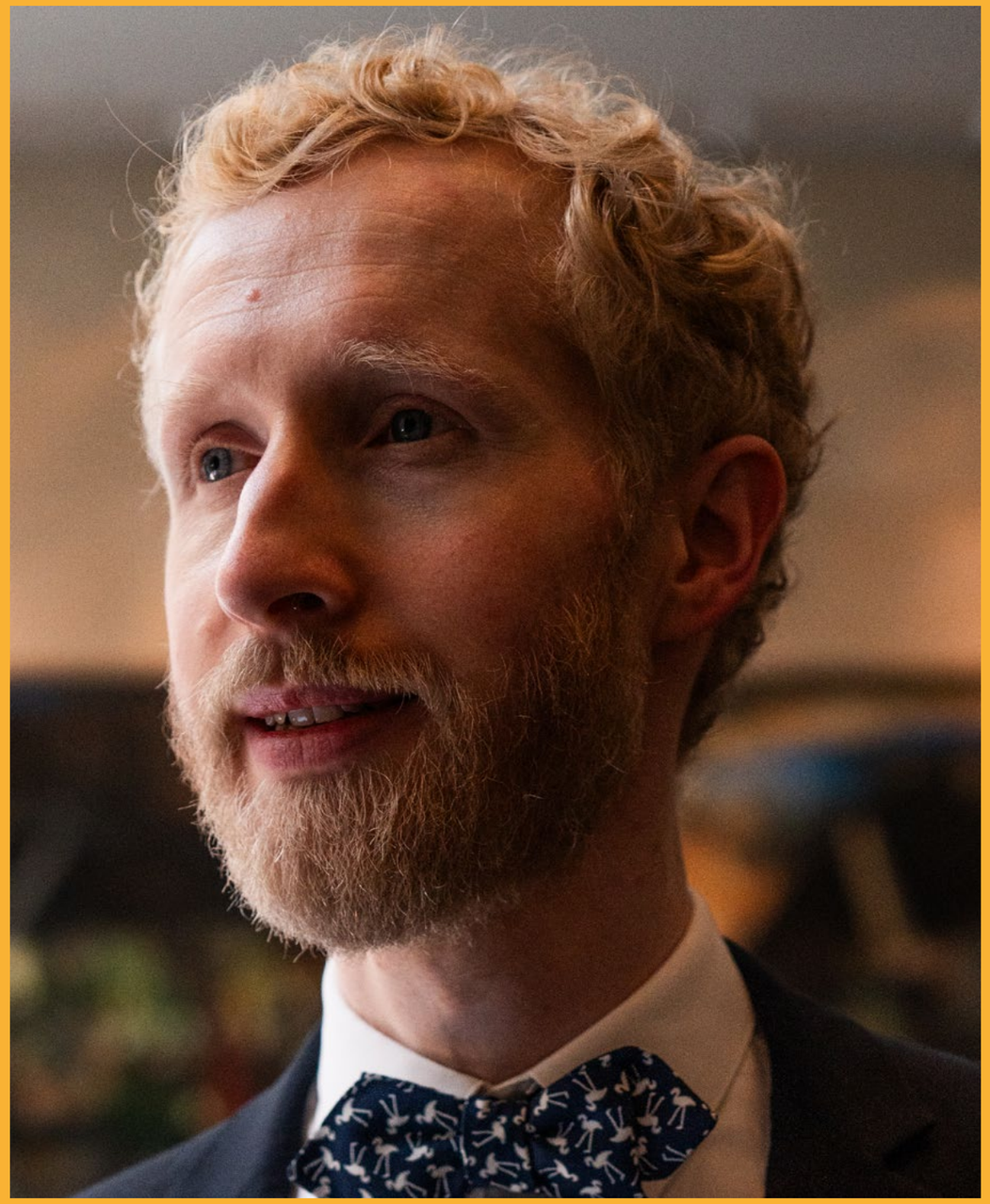
Looking back, 2025 has been one of the most remarkable years for the Global Albinism Alliance since its inception in 2020.

Two major conferences shaped the year: ISCA 2025, focused on biomedical research, opened January with record abstract submissions, and the first-of-its-kind World Forum on Skin Cancer, co-organized with ILDS and Standing Voice, closed it, highlighting our capacity as global drivers and conveners.

Advocacy reached new heights: after three years of joint work with the UN Expert on albinism and other partners, sunscreens for people with albinism were added to the WHO Essential Medicines List. I believe this success shows that, by giving the albinism community a global voice, the Alliance can help achieve major breakthroughs.

I was particularly pleased that we finally reconnected in person with our community for the first time since 2020, hosting two gatherings with around 50 member organizations. The hiring of our Communications Manager gave a much-needed boost to our communications: our newsletters, now Spotlight, returned, social media became more regular and professional, and blog articles showcased member achievements.

2025 truly exceeded my expectations and makes me look to 2026 with confidence. I am especially enthusiastic about the implementation of Global Albinism Alliance 2.0, which—thanks to the support of the Pierre Fabre Foundation—will help strengthen our governance, member engagement, and overall impact.



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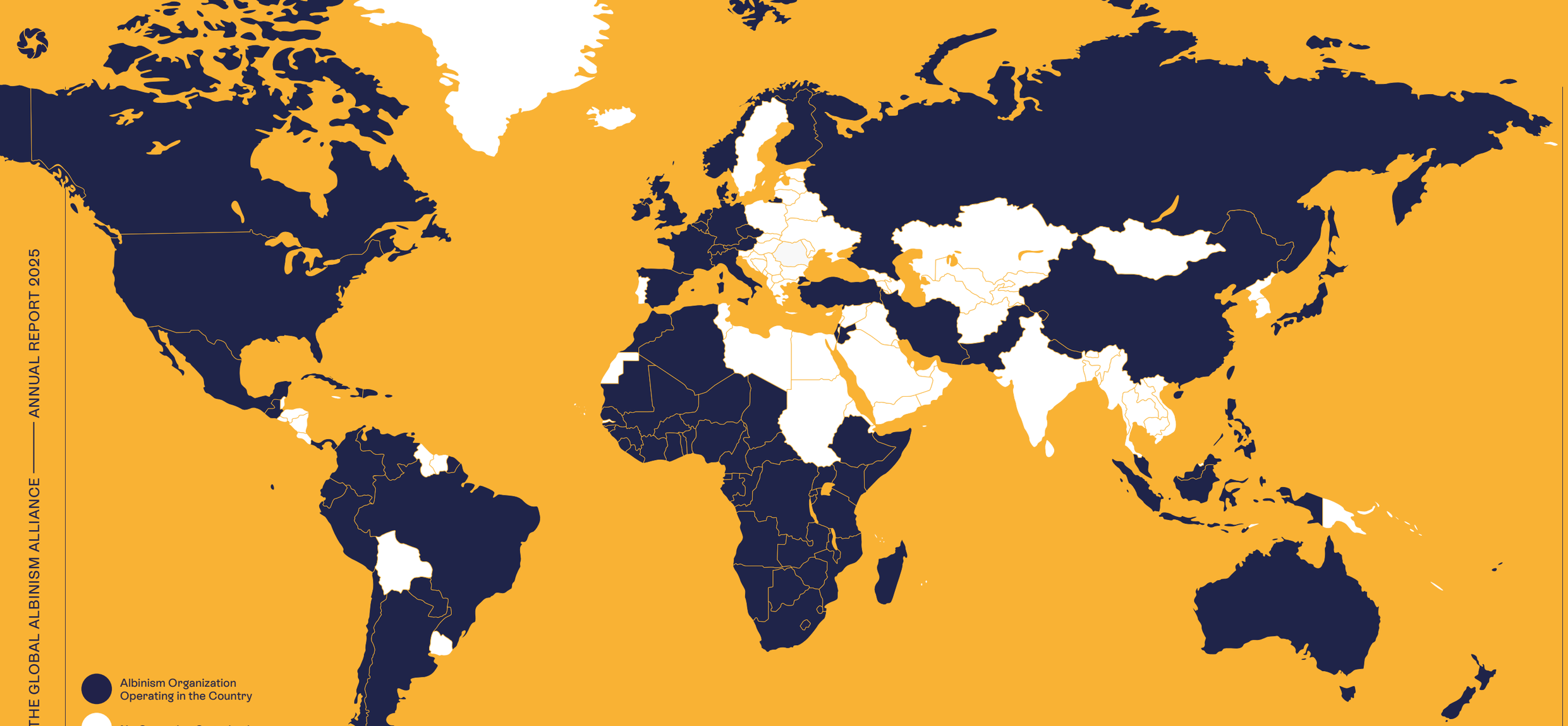

Albinism Organization Operating in the Country

No Operating Organization

**150+**

ALBINISM ORGANIZATIONS UNDER OUR UMBRELLA

**80+**

COUNTRIES REPRESENTED

**1 in 4,000 to 7,000**

PREVALENCE OF ALBINISM IN AFRICA

**1 in 12,000 to 15,000**

PREVALENCE OF ALBINISM IN EUROPE



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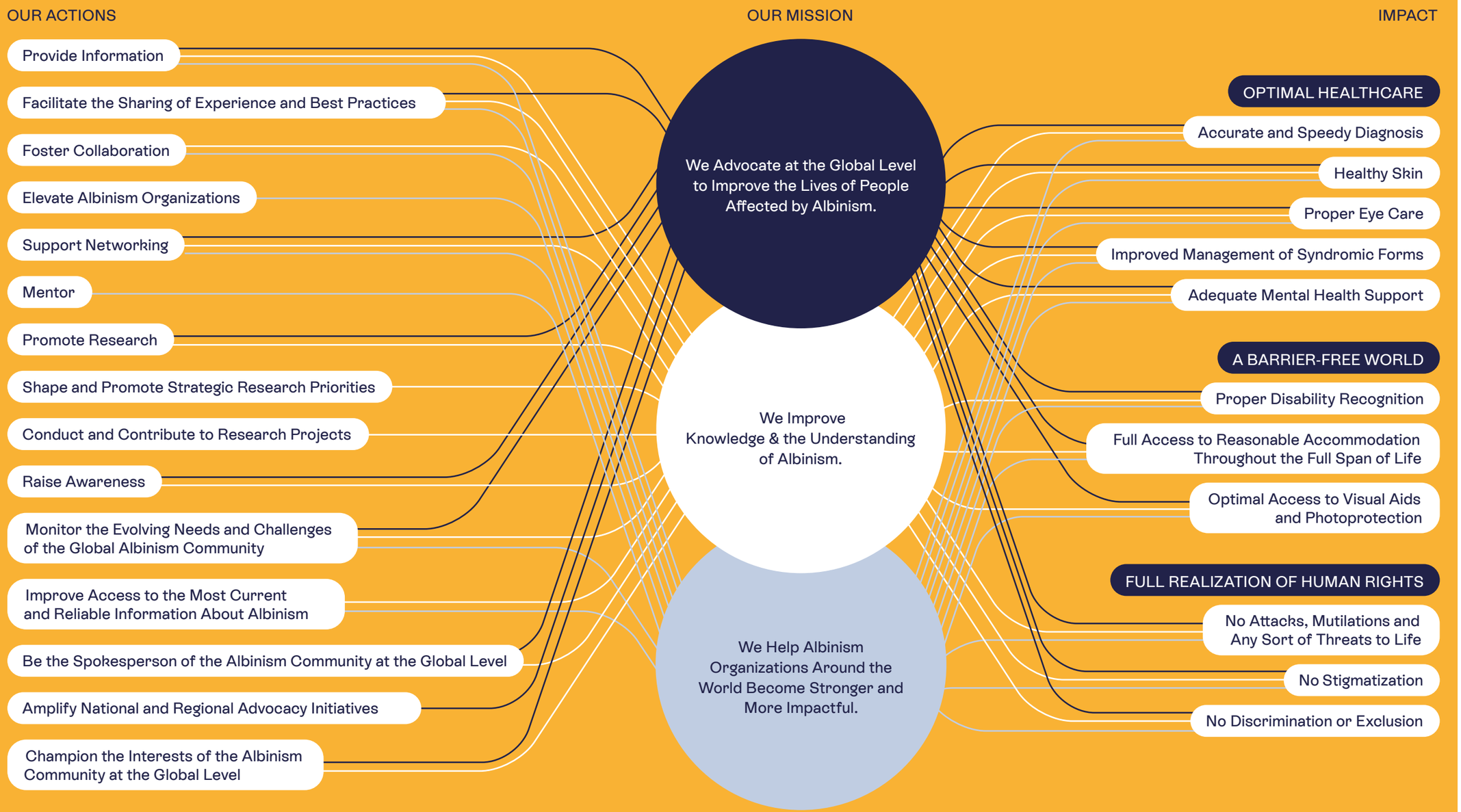
# HOW WE WORK






A World Where People With Albinism Have the Best Possible Quality of Life.

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# KEY HIGHLIGHTS OF 2025

**JANUARY 21–24**
ISCA 2025 Virtual scientific conference on albinism

**MARCH 05**
UNHRC Side Event 10 years of UN mandate on albinism

**MARCH 07**
UNHRC, Oral statement to UN Human Rights Council

**MARCH 24–26**
2nd World Meeting on Skin Neglected Tropical Diseases at the WHO

**23 APR 2025**
GAA Membership Meeting at Prague GlobalSkin Conference

**MAY 24**
WHA, Rare diseases resolution adoption

**MAY 24**
WHA, Skin diseases resolution adoption

**JUNE 16–19**
Geneva Advocacy Week in support of UN Mandate on Albinism

**17 JUNE**
IAAD Celebration at UN Geneva Headquarters

**01 JUNE**
First GAA Communications Manager recruited

**AUGUST**
Launch of @GlobalAlbinism X account

**SEPTEMBER 05**
Sunscreen added to WHO EML & EMLc

**SEPTEMBER 15–16**
International Conference on Albinism in Lancaster, UK

**OCTOBER 27–28**
First World Forum on skin cancer in PWA

**OCTOBER 29**
GAA Membership Meeting in Cape Town

**OCTOBER**
Launch of GAA Blog

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# INTERNATIONAL SCIENTIFIC CONFERENCE ON ALBINISM ISCA25

21–24 JANUARY 2025
ONLINE

Organised by the Global Albinism Alliance, ISCA25—*the latest edition of the International Scientific Conferences on Albinism* (ISCA)—was held online from 21–24 January 2025, with an additional follow-up session on 17 December 2025. The conference convened a record 188 specialists, advocates and persons with albinism from 45 countries, with the aim of strengthening diagnostic pathways, clinical management and therapeutic approaches, while keeping quality of life and holistic care at the centre of discussions.

The scientific program was developed with the guidance of a Scientific Advisory Committee composed of 16 internationally recognised experts from multiple disciplines. ISCA25 received a record number of 66 abstract submissions and delivered 42 selected presentations from

**188**
Attendees in 2025

**13+**
hours of albinism-focused scientific sessions

**43**
oral presentations and 16 posters

”

ISCA25 was an outstanding, well-organized event covering the full breadth of albinism research and care. Thursday's session spanned mechanisms to potential therapies; while NIH/NEI colleagues were missed, extended discussions proved energizing and collaborative. We also reflected on the lasting impact of leaders like Gail Summers and Arthur Bergen.

MERVYN THOMAS,
Ophthalmologist, Leicester (UK)

44 speakers and 16 posters, structured across four main tracks, representing more than 13 hours of expert content in total. Together, these sessions addressed key biomedical aspects of albinism, from genetics and ophthalmology to dermatology, neuroscience, psychology and clinical care, offering participants an up-to-date overview of advances and remaining gaps.

Beyond the formal sessions, ISCA25 was intentionally designed as a forum for exchange and collaboration. Through interactive Q&A, panel discussions, poster exchanges and two dedicated social gatherings, the conference created space for meaningful dialogue, cross-disciplinary networking and the start of new partnerships. This collaborative model helps ensure that emerging evidence is translated into practical solutions and more holistic management of albinism.

ISCA25 builds on momentum that began in 2012 with the launch of the *European Days of Albinism* (EDA), which later evolved into ISCA. With each edition, participation and scientific scope have grown, consolidating ISCA's role as a unique global platform—and "the" meeting point worldwide—for advancing biomedical knowledge on albinism and improving health for persons with albinism. Following two online editions, the Global Albinism Alliance now aims to return ISCA to an in-person format in 2027, to further deepen scientific exchange, foster mentorship (especially for early-career researchers and clinicians), and strengthen engagement between the scientific community and albinism organisations worldwide.



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← Julio, Fondation Julio Levotre, DRC

**66**
Abstracts / 50 for ISCA 2022

**45**
Speakers
/ 31 for ISCA 2022

**16**
Posters
/ 8 for ISCA 2022

"The standard was stratospherically improved compared to the dermatology offering at the last meeting. Great platform and very well organised. I really appreciated the opportunity to participate.

CLAIRE FULLER,
Dermatologist, London (UK)
Chair of the International Foundation for Dermatology

Stéphanie, Association de lutte pour le bien-être des albinos, Gabon →

## MULTI-STAKEHOLDER COALITION BEHIND THE WHA RESOLUTION "SKIN DISEASES AS A GLOBAL PUBLIC HEALTH PRIORITY"

January–March, 2025
online

In the first months of 2025, *the Global Albinism Alliance* contributed to *the World Skin Health Coalition's* advocacy efforts toward a *World Health Assembly (WHA)* resolution. Adopted on May 24, the resolution recognises skin diseases as a global health priority. By providing input on the specific needs and challenges faced by persons with albinism, *the GAA*, in collaboration with *BEDA-CI*, the albinism organisation of Côte d'Ivoire, helped ensure that the burden of skin cancer and other skin-related challenges associated with albinism was recognised alongside other rare and chronic skin conditions. This collaboration strengthened the case for more inclusive health policies and reinforced the *GAA*'s role within the wider international dermatological patient community.

## MULTI-STAKEHOLDER COALITION BEHIND THE WHA RESOLUTION "RARE DISEASES: A GLOBAL HEALTH PRIORITY FOR EQUITY AND INCLUSION"

January–March, 2025
online

*The Global Albinism Alliance* was proud to join Rare Diseases International and other partners in the multi-stakeholder coalition that successfully advocated for the adoption in May 2025 by the *WHA* of a resolution recognising rare diseases as a global health priority. By sharing the perspective of persons with albinism, the *GAA* helped ensure that our diverse global community is included in global efforts to advance equity, inclusion and universal health coverage for people living with rare conditions.


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© Dominik Kuděra

← Teresa, Fundacion piel de Luna albinos de México, México

## CELEBRATION OF THE 10TH ANNIVERSARY OF THE UN MANDATE ON ALBINISM

5 March 2025
United Nations, Geneva, Switzerland

*The Global Albinism Alliance* was honoured to take part in an event marking the 10th anniversary of the resolution establishing the mandate of the *UN Independent Expert on the enjoyment of human rights by persons with albinism.* During this event, held on the sidelines of the *UN Human Rights Council* session, Executive Director Antoine Gliksohn highlighted in his remarks the progress made and ongoing challenges.

© UN Photo / Jean Marc Ferré

## ORAL STATEMENT AT THE 58TH UNITED NATIONS HUMAN RIGHTS COUNCIL

7 March 2025
United Nations, Geneva, Switzerland

During the 58th Regular Session of the *United Nations Human Rights Council (UNHRC)*, the *Global Albinism Alliance (GAA)*, together with *International Service for Human Rights (ISHR)*, delivered an oral statement in response to the latest report marking the 10th anniversary of the mandate of *the UN Independent Expert on the enjoyment of human rights by persons with albinism.*
In his intervention, *the GAA* Executive Director Antoine Gliksohn underlined that “while significant progress has been made over the past decade, the rights of persons with albinism remain today a serious concern throughout the world.”

Pablo, Albinismo solidario asociado, Spain & Dominican Republic →

## SECOND WORLD MEETING ON SKIN-RELATED NEGLECTED TROPICAL DISEASES (NTD)

March 24–26, 2025
WHO, Geneva, Switzerland

In March, *the GAA* had the opportunity to contribute to the Second World Meeting on *Skin-Related Neglected Tropical Diseases (NTDs)* at the *World Health Organization* in Geneva, held under the theme "Integration to Achieve 2030 Targets". The meeting focused on integrating skin NTDs into health systems to meet the WHO NTD Road Map 2021–2030 goals. Although skin cancer in persons with albinism is not yet officially listed as an NTD, it meets all the criteria. Pending formal recognition, there may be opportunities for people with albinism affected by skin cancer to benefit indirectly from certain skin NTD programs and health system platforms. Securing formal recognition and listing remains one of the GAA's key global advocacy priorities, and The GAA used this platform to engage with NTD experts and policymakers.

© GlobalSkin

## GLOBALSKIN BIANNUAL CONFERENCE

April 24–27, 2025
Prague, the Czech Republic

*The Global Albinism Alliance* took part in the biannual GlobalSkin Conference held in Prague in April. It began with the *RareDERM Forum* and continued through three days of sessions under the theme "Champion". The event brought together patient organization leaders as well as a selection of the world's leading dermatologists and experts from all regions to inspire, connect and strengthen the global dermatology patient voice. For the GAA, it was a key opportunity to network, share experience, learn new advocacy tools and build partnerships to better address challenges affecting people with albinism worldwide.


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# GLOBALSKIN CONFERENCE SIDE-MEETING

23 APRIL 2025
PRAGUE, CZECH REPUBLIC

PHOTO BY DOMINIK KUČERA

On April 23, t*he Global Albinism Alliance (GAA)* reunited albinism leaders from all regions at a landmark side meeting in Prague—the first global in-person membership gathering since the GAA exploratory meeting held in Paris in 2020. Organised one day before the *GlobalSkin Conference*, and building on the presence of participants already in the city for this major international skin advocacy event, the meeting provided a unique setting for albinism organization leaders to connect in person.

The gathering brought together 24 leaders from 19 albinism-focused organisations, representing all regions of the world. Over the course of a full day, participants were introduced to the GAA 2020–2025 Activity Report and took part in dedicated sessions on the *UN Mandate on Albinism*, *International Albinism Awareness Day 2025*, the GAA Skin Cancer Program, and the GAA's structure, membership, and governance. The agenda also included a discussion on European collaboration, as well as a workshop on "The Global Landscape of Albinism Organisa-

tions: Dynamics and Collaborations", offering a comparative view of how albinism organisations operate and cooperate in different regions.

The side meeting pursued four main goals:
— to update albinism organisations on the GAA's activities;
— to provide an open Q&A space for questions, feedback, and concerns;
— to co-create priorities for the GAA's work over the next five years; and
— to strengthen the community by giving leaders the chance to get to know one another better.

These objectives, reflected in the structure of the day, balanced presentations with open dialogue, group discussions, and informal interaction. A social dinner in the evening further deepened connections and helped build trust and solidarity among leaders who often work in very different contexts but face similar challenges.

*The Global Albinism Alliance* extends its sincere thanks to *GlobalSkin* for making this side meeting possible by providing a space where albinism advocates could meet within the broader skin health community. The Prague side meeting marked an important moment in the GAA's role as a facilitator and connector for the global albinism community. By bringing together leaders from 19 organisations, the GAA helped renew momentum for regional collaboration and reinforced a sense of shared purpose. The results of this meeting are being used to guide current work on membership, governance, regional networks, and support for national organisations. This ensures that the Alliance continues to act together with and in support of its community.

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I loved it — PETER OGIK

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It was great to meet other organization leaders from around the world, especially within the albinism community. I enjoyed getting to know people throughout the conference and feel that organizations in the "rare" category have many common areas to relate and discuss. I truly felt a connection in raising our voices as one.
— KAREN BLY

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The GAA Prague side event was a timely, meaningful, and powerful moment that brought our global community together, and I'm truly proud to be part of it.
– HARRY FREELAND

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The great work that Antoine does with the GAA strengthens us to continue working more in our countries. Being among many world representatives with the same objectives filled my heart with strength.
— JORGE RODRIGUEZ BIZARRO

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Inspiring! — JO BENNETT

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← Patric, National Albinism Task Force, South Africa

## 21ST FRENCH NATIONAL CONFERENCE ON PHOTOBIOLOGY AND PHOTODERMATOLOGY

May 14-16, 2025
Paris, France

*The Global Albinism Alliance* was kindly invited to attend the joint congress of the *French Society of Photodermatology*, the *French Society of Photobiology* and the "Black Skin" thematic group of the *French Society of Dermatology* in Paris. Sharing a stand with *GENESPOIR* (the French albinism association), the GAA helped raise awareness among specialists about the specific needs and challenges of the global albinism community and the importance of tailored photoprotection and care. The congress also provided an excellent opportunity for the GAA to stay up to date on the latest research on photoprotection and the effects of UV radiation on the skin.

## SKIN DISEASES AS A GLOBAL HEALTH PRIORITY

20 May 2025
Geneva, Switzerland

*The Global Albinism Alliance* was present at a WHA side event in Geneva, co-hosted by *GlobalSkin*, on the draft World Health Assembly resolution recognising skin diseases as a global public health priority. The high-level meeting brought together health ministry representatives from lead and co-sponsoring countries, alongside civil society. For the GAA, it was an important moment to underline that people with albinism must be included in global efforts to improve prevention, diagnosis and care for skin diseases, and to thank *GlobalSkin* for its leadership in bringing the patient voice to the *WHA*.

Elif, Albinizm Derneği, Turkey →


© Elif Nur Kaylar

## MILESTONES & MOMENTUM IN RARE DISEASES: 10 YEARS OF PROGRESS, 10 YEARS OF POSSIBILITY

21 May 2025
Geneva, Switzerland

On the margins of *WHA78* in Geneva, the GAA also attended a side event organised by Rare Diseases International and partners to highlight the importance of the proposed *WHA Resolution on Rare Diseases*. The meeting brought together health ministers, officials, clinicians, civil society and people living with rare conditions to reflect on a decade of progress and to outline the next phase of advocacy and policy. The GAA was proud to participate and reiterate its support for universal health coverage for persons living with rare diseases and conditions, including albinism.

## 44TH CONGRESS OF THE EUROPEAN STRABISMOLOGICAL ASSOCIATION (ESA)

11–14 June 2025
Istanbul, Turkey

At *the 44th Congress of the European Strabismological Association (ESA)*, a key meeting for paediatric ophthalmology, nystagmus and strabismus specialists, *the Global Albinism Alliance* was represented by Elif Nur Kayalar from *Albinizm Derneği*, the Turkish organisation for people with albinism. Thanks to her advocacy and expertise, eye care professionals learned more about the specific needs and realities of people with albinism, strengthening understanding and improving future care.

© Dominik Kučera

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← Souradji, Association nationale des personnes atteintes d'albinisme au Togo, Togo

## MARKING INTERNATIONAL ALBINISM AWARENESS DAY AT THE UN

17 June 2025
United Nations, Geneva

For the second year in a row, t*he Global Albinism Alliance* co-organised an *International Albinism Awareness Day (IAAD)* celebration at the UN in Geneva, Under the theme "Demanding our rights: Protect our skin, Preserve our lives", the event featured the launch of a photo exhibition by Pierre-William Henry, showcasing portraits and testimonies of persons with albinism in Central Africa. *The Global Albinism Alliance* is deeply grateful to *the United Nations Office* at Geneva for the opportunity to co-host this celebration at *the Palais des Nations* and to raise awareness of the burden of albinism in one of the world's most important decision-making spaces.

## ADVOCACY INITIATIVE FOR THE UN MANDATE ON ALBINISM

16–19 June 2025
United Nations, Geneva

*The Global Albinism Alliance* led an advocacy initiative in Geneva to support the *UN Mandate on Albinism* on the occasion of *International Albinism Awareness Day*. A delegation of 10 representatives from albinism organisations, met with *the President of the UN Human Rights Council*, Jürg Lauber, and 18 Permanent Missions of UN Member States. Against the backdrop of a broader UN financial crisis, the GAA-led delegation emphasized the vital and unique role of the mandate in protecting and promoting the rights of persons with albinism and urged that it not be questioned, compromised or discontinued.

Peter, Source of the Nile Union of Persons with Albinism, Uganda →

## LAUNCH OF X ACCOUNT

August 2025

The Global Albinism Alliance launched its new account on X (@GlobalAlbinism). Focused on advocacy and policy engagement, the X account will help amplify the voices of persons with albinism, share timely updates from global processes, and reach decision-makers, journalists and partners more directly. This new channel complements the GAA's existing social media presence and strengthens its capacity to communicate and mobilise at global level.

## WHO - INTERNATIONAL ADVISORY COMMITTEE MEETING ON NON-IONIZING RADIATION - 14TH MEETING OF THE OPTICAL PROGRAMME

June 17, 2025
Online

As every year since 2023, *the GAA* was invited by the *World Health Organization's Radiation & Health Unit* to participate in the International Advisory Committee Meeting on Non-Ionizing Radiation. This year, Valerie McCormack from *the International Agency for Research on Cancer (IARC)* presented to the expert committee an overview of ongoing and future projects conducted by her team in collaboration with *the Global Albinism Alliance, Standing Voice*, and other stakeholders to collect and analyze data on the epidemiology of skin cancer in persons with albinism.

© Kasey Davidson

# WHO RECOGNITION OF SUNSCREEN AS AN ESSENTIAL MEDICINE

5 SEPTEMBER 2025
GENEVA, SWITZERLAND

*The Global Albinism Alliance (GAA)* achieved a major advocacy milestone when *the World Health Organization (WHO)* approved the inclusion of broad-spectrum sunscreen for people with albinism on the 24th *Model List of Essential Medicines (EML)* and the 10th *Model List of Essential Medicines for Children (EMLc)*. This decision represents a transformative step in protecting persons with albinism from preventable, UV-induced skin cancer.

The inclusion is the result of a rigorous global application submitted by the GAA in November 2024, in partnership with the *UN Independent Expert on the enjoyment of human rights by persons with albinism*, the *UN Special Rapporteur on human rights and climate change*, and key collaborators including *Standing Voice*, *Beyond Suncare*, *Fondation Pierre Fabre*, *the International League of Dermatological Societies (ILDS)* and the *Africa Albinism Network*. This coalition demonstrated the power of coordinated, multi-stakeholder advocacy in advancing health equity for persons with albinism.

The *WHO EML* and *EMLc* are globally recognised reference tools that guide national medicine policies, procurement and reimbursement decisions. By listing broad-spectrum sunscreen, the *WHO* has effectively confirmed that, for persons with albinism, sunscreen is not a cosmetic product but a life-saving health intervention. This designation paves the way for integration of sunscreen provision into public health systems, improved affordability and more reliable supply – especially in high-UV, low-resource settings where access to photoprotection is most limited.

For albinism organisations worldwide, the decision provides a powerful new advocacy lever. It strengthens their ability to:

— push for inclusion of sunscreen on national essential medicines lists,
— negotiate with governments and health insurers for reimbursement and public provision,
— secure funding and partnerships to scale up skin cancer prevention programmes, and
— argue for stronger recognition of skin cancer in persons with albinism as a neglected health priority.

*The Global Albinism Alliance* is building on this breakthrough by supporting member organisations with advocacy strategies, capacity building and education on sun protection, including sunscreen, UV-protective clothing and hats. *The WHO* decision also underpins the GAA's broader work on skin cancer, including the organisation of the *World Forum on Skin Cancer Prevention and Management in Persons with Albinism*, and ongoing efforts to develop global standards for monitoring and reducing the burden of skin cancer in this population.

Constance, Live together as family, Burundi →

## 20TH INTERNATIONAL CONGRESS OF DERMATOLOGY IN MADAGASCAR (SOMADER)

1–2 July 2025
Online (hosted from Madagascar)

*The Global Albinism Alliance* took part in *the 20th SOMADER Congress on Dermatology*, focused on dermatology in the age of AI, skin neglected tropical diseases and innovation. The GAA's Executive Director, Antoine Gliksohn, delivered a presentation on "Albinism in Madagascar and Worldwide: Assessing Needs and Challenges", helping to raise awareness among dermatology experts in this part of the world about the specific realities and care needs of persons with albinism.

## INTERNATIONAL CONFERENCE ON ALBINISM

16–17 September 2025
Lancaster, United Kingdom

*The Global Albinism Alliance* participated in *the International Conference on Albinism* at *Lancaster University*, marking 10 years of the UN mandate on albinism. The event, co-organized by Professor Charlotte Baker from *the School of Global Affairs*, brought together albinism association leaders, clinicians and researchers to share findings and discuss key challenges. Antoine Gliksohn, the GAA's Executive Director, delivered an oral presentation on albinism organisations in the global context, joined a panel on albinism in the UK, and chaired a second panel on advocacy.

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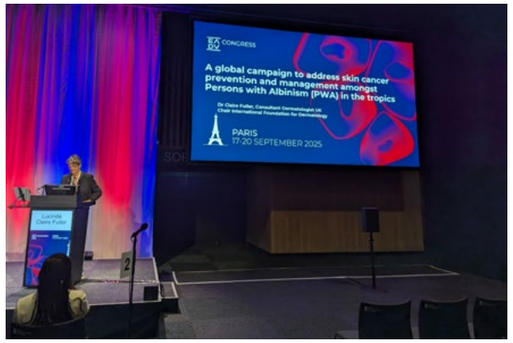


## EADV CONGRESS

17–20 Sep 2025
Paris, France

The 2025 *European Academy of Dermatology and Venereology (EADV) Congress*, Europe's largest dermatology meeting, took place in Paris and brought together over 20,000 delegates, offering a unique platform for networking, exchange, and new partnerships. As in previous years, *the Global Albinism Alliance* participated to raise awareness of the challenges faced by persons with albinism and to connect with existing and potential partners.
*The EADV Congress* also serves as the venue for the annual meeting of the *EADV Advocacy Task Force*, of which the GAA Executive Director is a member.


## ALBINISM BEYOND 2030

17–20 Sep 2025
Bloemfontein, South Africa

The international conference *Albinism Beyond 2030*, hosted by the University of the Free State in Bloemfontein, brought together advocates, experts, and community representatives to discuss the realities and future of albinism advocacy in South Africa and beyond. *The Global Albinism Alliance* participated to contribute to the exchange, deepen its understanding of the South African context, and strengthen connections with local stakeholders. The conference also highlighted the lifelong advocacy of Nomasonto Grace Mazibuko, known as Ma Nomasonto, a key figure in the South African albinism community and in the global movement for the rights and visibility of persons with albinism.

# WORLD FORUM ON SKIN CANCER PREVENTION & MANAGEMENT IN PERSONS WITH ALBINISM

27 – 28 OCTOBRE 2025
CAPE TOWN, SOUTH AFRICA

PHOTO BY JODI WINDVOGEL

At the end of October 2025, *the Global Albinism Alliance (GAA)*, together with the *International League of Dermatological Societies (ILDS)* and *Standing Voice*, co-organised the first-ever *World Forum on Skin Cancer Prevention and Management in Persons with Albinism* in Cape Town, South Africa. Held on 27–28 October at *the Westin Hotel*, the Forum was conceived as a landmark, in-person gathering to address one of the most urgent health challenges facing persons with albinism: preventable skin cancer, whose incidence can be up to 1,000 times higher than in the general population in sun-intense regions such as sub-Saharan Africa.

The Forum brought together around 70 delegates from 30 countries, forming the first global

coalition of stakeholders dedicated specifically to skin cancer in persons with albinism. Participants included leaders of national, regional and global albinism associations; experts from NGOs and foundations running skin cancer program; clinicians, dermatologists, surgeons, pharmacists and global health specialists; researchers including cancer epidemiologists from *the International Agency for Research on Cancer (IARC)*; leaders of dermatological societies; and a representative of *the World Health Organization (WHO)*. The event was primarily supported by *the Pierre Fabre Foundation*, with additional contributions from *ISDIN*.

Building on WHO's recent decision to include broad-spectrum sunscreen for persons with albinism on the *Essential Medicines Lists* (EML and EMLc), the Forum served as a global catalyst for action. Through plenary sessions, workshops, panel discussions and collaborative breakouts, delegates worked to quantify the burden of skin cancer in albinism, examine barriers to prevention and care, share programme experience from the field, and identify scalable, evidence-based strategies for prevention, early detection and treatment. Key sessions covered epidemiological data, innovative screening models, policy advocacy for sunscreen affordability and access, and community-led education and empowerment.

A central achievement of the meeting was agreement on key outcome areas and next steps. Participants established working groups tasked with developing a comprehensive global plan of action around five pillars:

— Advocacy and communication, leveraging *the World Health Assembly* resolution on skin diseases as a global public health priority, pursuing potential WHO neglected tropical disease recognition for skin cancer in persons with albinism, and strengthening public awareness through campaigns and social media;
— Access to photoprotection, capitalising on WHO's inclusion of sunscreen in the EML/EMLc and promoting complementary protective measures;
— Clinical capacity-building, including training for screening, diagnosis and surgical management;
— Scaling up surveillance and treatment services;
— Prioritising research, with support from IARC for data collection and analysis.

The Forum builds on recent advances in global health recognition of skin conditions and aligns

closely with the GAA's broader work on skin cancer prevention and the right to health. It marked an important step in shifting from fragmented efforts to a coordinated, multi-sectoral response, rooted in both clinical expertise and the lived experience of persons with albinism. *The Global Albinism Alliance, ILDS* and *Standing Voice* closed the meeting with a joint call for governments, health organisations and the international community to support this emerging movement, and committed to sustaining the partnerships and working groups launched in Cape Town in the years ahead. will certainly allow us to work according to a clear directive.

# MEMBERSHIP MEETING

29 OCTOBRE 2025
CAPE TOWN, SOUTH AFRICA

PHOTO BY JODI WINDVOGEL

Building on the momentum generated by *the World Forum on Skin Cancer Prevention and Management in Persons with Albinism*—and the opportunity to bring participants together in one place—*the Global Albinism Alliance* hosted a dedicated side meeting for its member-organizations in Cape Town. The event brought together 32 leaders of associations of persons with albinism and NGO serving the albinism community. It provided a valuable opportunity to convene in one place, reflect on the World Forum's discussions, and focus specifically on the needs and priorities of the albinism community around the world.

The one-day programe combined updates from the GAA with strong contributions from member organisations and partners. The meeting opened with brief five-minute presentations from each organisation in attendance, followed by an overview of the GAA's Work (2020–2025). A series of thematic presentations then high-

lighted regional and global developments, including the official launch of *the Latin American Union of Albinism (ULA)* by Pablo Delgado (Dominican Republic), an overview of the skin cancer situation in Latin America by Julio Garcia (Argentina), an update on the structuring of *the Association of Persons with Albinism in Brazil (APALBR)* by Joselito Pereira da Luz, and *the Africa Albinism Network's 10-year vision* for collective action presented by Bonface Massah (Malawi).

The afternoon program showcased a range of long-standing and emerging initiatives from different regions. Presentations covered a 17-year journey supporting persons with albinism through *Beyond Suncare* (Mafalda Soto), the impact of climate change on skin cancer risk among persons with albinism in Zimbabwe (*The Noble Hands Zimbabwe Trust*, Willard Musiyarira), a human-rights-based comprehensive support programme in Mozambique (*Africa Directo*, Catalina Lavandeira), and the role of education in social inclusion (*Fondation Julio Levotre*, Julio Tukadi). Later sessions explored mental health and skin conditions (*Corbetta RDC*, Gaylord Inena) and concluded with a presentation by the GAA's Executive Director, Antoine Gliksohn, on the Alliance's past work and future priorities. Throughout the day, breaks and informal exchanges helped deepen the personal and professional connections initiated during the World Forum.


*The Global Albinism Alliance* sees this side meeting as an important step in its role as a facilitator and connector for its membership. Insights from Cape Town are feeding directly into the GAA's work on membership, governance, regional networks, and support for national organisations—helping ensure that the momentum created by the World Forum translates into stronger, more connected action for persons with albinism worldwide.

Jorge, Fundacion piel de Luna albinos de México, Mexico →

## PARTICIPATION IN A BRAZILIAN WEBINAR ON THE WHO SUNSCREEN DECISION

23 Sep 2025
Online

*The Global Albinism Alliance* was proud to take part in a Brazilian webinar on the WHO decision to include sunscreen on *the Model Lists of Essential Medicines*. Alongside the UN Independent Expert on albinism and albinism organisation leaders from across Latin America, the GAA's Executive Director analyzed the WHO's decision in detail, reflected on the advocacy work that led to this outcome and highlighted key points of the application. He then emphasized the need for joint efforts to turn this global decision into real, equitable access in the region.

## LAUNCH OF SPOTLIGHT THE GAA'S NEWSLETTER

October 2025

In October, the Global Albinism Alliance launched its new bi-monthly newsletter, *Spotlight*. This digital channel brings together updates on the GAA's work, highlights from albinism organisations worldwide, calls for projects, opportunities, events, data-sharing initiatives and recent scientific articles across disciplines. *Spotlight* aims to provide advocates, professionals and organisations with a single source of key information and developments from across the world of albinism.

© Dominik Kuĉera

© Jodi Windvogel

← Newton, Ghana Association of persons with Albinism, Ghana


## ALBINISM FELLOWSHIP CONFERENCE 2025 “STRENGTH IN RESILIENCE”

7–9 November 2025
Swanwick, United Kingdom

*The Global Albinism Alliance* was invited to the *Albinism Fellowship UK & Ireland* Conference 2025, themed “Strength in Resilience”, a family-friendly weekend bringing together children, adults and families with albinism from across the UK and Ireland. Represented by Executive Director Antoine Gliksohn, the GAA used this opportunity to hear lived experiences and gain a deeper understanding of the day-to-day challenges in education, employment, low vision and mental health faced by our community in this part of Europe. The conference offered parallel programmes for adults, children and teens, focused on building confidence, sharing experiences and supporting people with albinism to embrace their identity and thrive.

## JOURNÉES DERMATOLOGIQUES DE PARIS 2025

2–6 December 2025
Paris, France

In December, as every year since 2021, *the Global Albinism Alliance* was present at *the Journées Dermatologiques de Paris (JDP)*, one of the main international meeting points for French-speaking dermatologists. The congress brought together 7,275 participants and offered a key platform to discuss skin cancer, photoprotection and clinical care in albinism. For *the GAA*, it was an opportunity to connect with experts, exchange insights and help keep albinism firmly on the dermatology agenda.

Karen, NOAH, USA →

## RÉUNION ISLAND ONCO-DERMATOLOGY DAY

November 20, 2025
Online (hosted from Réunion Island)

The GAA's Executive Director was invited to speak on albinism and skin-related issues at Réunion Island's annual Onco-Dermatology Day. In this French overseas territory, located east of Madagascar in the Indian Ocean, albinism has so far received limited national and international attention, while the combination of a tropical climate and high levels of poverty contributes to frequent diagnoses of cancerous and pre-cancerous lesions, as well as significant barriers to education for people with albinism. The meeting laid the foundation for a promising collaboration aimed at improving knowledge about albinism and strengthening support for people with albinism in this part of the world.

## ERN-SKIN BOARD MEETING 2025

11–12 December 2025
Institut Imagine, Paris, France

The last meeting of the year for *the Global Albinism Alliance* was the Board Meeting of *the ERN-Skin*, *the European Reference Network* of experts dedicated to improving diagnosis, treatment and care for patients with rare and complex skin conditions. Held over two days in Paris, the meeting provided an opportunity to review progress since the previous board meeting, including work on *the ERN-Skin registry (ERRAS)*, monitoring and communication tools, and disease-group activities. With regard to albinism, discussions addressed the contribution of the *ERN Skin* to *ISCA 2025*, the need to strengthen clinical data collection to better document skin-related epidemiology in Europe and the advocacy initiatives following the inclusion of sunscreen on the *WHO Model List of Essential Medicines*.

© Dominik Kučera

← Kenneth, Danish association for albinism, Denmark

## ALBINISM VARIANT CURATION EXPERT PANEL

online

The work of *the Albinism Variant Curation Expert Panel (Albinism VCEP)* began in 2023 and, coordinated by the Global Albinism Alliance, continued throughout 2025. The panel is co-chaired by Dr. David Adams (National Institutes of Health, Bethesda, USA) and Dr. Panagiotis Sergouniotis (University of Manchester, United Kingdom).

*The Albinism VCEP* is a specialized expert group operating under the *Clinical Genome Resource (ClinGen)* initiative. Its core goal is to improve the clinical interpretation of genetic variants in genes associated with albinism. By delivering consistent, high-confidence variant interpretations, the *Albinism VCEP* aims to enhance diagnostic accuracy for individuals and families affected by albinism, support clinicians in making informed clinical decisions, and contribute to a globally accessible resource of high-quality, expert-curated genetic information.

Progress during the period was significantly affected by several disruptions linked to the political context in the United States, which placed the panel's work on hold for approximately half of the year and limited overall advancement.

As a result, work on the *OCA2* gene initially planned for 2025 will only commence in 2026, while the gene-specific rule specifications for *TYR* remain under development.

## CONTRIBUTIONS TO UN IE THEMATIC REPORTS

As part of its ongoing collaboration with *the UN Mandate of Albinism*, *the GAA* was pleased to contribute to the consultations held by the UN Independent Expert for the preparation of her two most recent annual thematic reports: *The Right to Health and Persons with Albinism in the Context of Skin Cancer* (presented in November 2025 at *the UN General Assembly*) and *Persons with Albinism and the Right to Employment* (to be presented in March 2026 at *the UN Human Rights Council.*

## CONTRIBUTIONS TO THE SCIENTIFIC ARTICLE ON NON-MELANOMA SKIN CANCER AND HPV IN PERSONS WITH ALBINISM: A CALL FOR RESEARCH INVESTMENT

In 2025, *the Global Albinism Alliance* contributed to a Perspective in *the British Journal of Cancer* (4 July), developed with *the International Agency for Research on Cancer (IARC)* and partners. The article highlights the urgent need for investment to better understand links between HPV and non-melanoma skin cancer in people with albinism, and explores HPV vaccination as a potential risk-reduction tool. It underscores the importance of integrated, evidence-based skin-cancer prevention policies. It strengthens the case for action.

# SOCIAL MEDIA, NEWSLETTER & WEBSITE OVERVIEW

**INSTAGRAM**

Impression 284K
Follow 1,2K / 815 new follow in 2025
Content interaction 8.6K

**FACEBOOK**

Impression 261.8K
Follow 2,8 K / 601 new follow in 2025
Content interaction 11.5K

**LINKEDIN**

Impression 125.1K
Follow 1,2K / 420 new follow in 2025
Content interaction 2.1K

**NEWSLETTER**

Subscribes 4,7K
Opening rate 32 %

**WEBSITE** from 09/25

Active users 2,7K
Event count 14K
Bounce rate 43,2%

**5,2K**
Total Social Media follow / 2,2K new follow in 2025

**670,1K**
Total post impression in 2025

**22,2K**
Total content interaction in 2025

**4,7K**
Newsletter subscribers

**14K**
Website event count in 2025

**43,2%**
Website bounce rate

Kristina, Albinism Fellowship, UK

© Dominik Kućera

# PEOPLE IN THE GLOBAL ALBINISM ALLIANCE

## Antoine Gliksohn

EXECUTIVE DIRECTOR, FRANCE

Antoine is the Executive Director of the Global Albinism Alliance, where he oversees strategic planning, organizational development, and daily operations. Before joining the Alliance, he worked in Paris as a Project Engineer on a major metro project. Antoine, the youngest of three siblings with albinism, is also an award-winning patient advocate.

## Carol Prendergast

PRESIDENT, USA

Carol is Chair of the Global Albinism Alliance, where she champions the human rights of persons with albinism. Prior to this, she worked as an attorney, program director, consultant, and board member for leading human rights NGOs, and served as a Senior Fellow in Human Rights at the London School of Economics.





## Sonia Daňková

COMMUNICATIONS MANAGER, CZECHIA

Sonia is the Communications Manager at the Global Albinism Alliance, where she leads external communications and community building across the global albinism network. Prior to joining the Alliance, she worked as an Art Director in a graphic design studio and for two local editions of Global Media. She is also the mother of a son with albinism.

## Kelsey Thompson

SECRETARY, USA

Kelsey currently serves as the GAA Secretary. She is a long-time volunteer with the National Organization for Albinism and Hypopigmentation (NOAH) in the United States, having previously served on the NOAH Board of Directors and as the Editor in Chief of the organization's quarterly newsletter. Professionally, Kelsey has worked for almost 20 years in the field of rehabilitation counseling.

# PEOPLE IN THE GLOBAL ALBINISM ALLIANCE

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## Elizabeth Beales

ADMIN VOLUNTEER, AUSTRALIA

Elizabeth is an admin volunteer at the GAA and is currently president of the albinism fellowship of Australia. With a background in Library and Information Services, she is dedicated to advancing accurate education and awareness about albinism, and supporting individuals and families, especially those with newly diagnosed children, by fostering connection and understanding within the community

## Julio Garcia

LIAISON FOR LATIN AMERICA, ARGENTINA

Julio is the Regional Liaison for Latin America at the Global Albinism Alliance. He works as a Project Manager at Rosario Traducciones and has earned multiple certifications from the Localization Institute, GALA, and California State University, Chico. Julio is the father of a daughter with albinism, co-founded the Argentine organization Fundación de Albinismo Simplemente Amigos, and serves as the Secretary of the Latin American cluster (ULA).

Rosiane, Coletivo Nacional das Pessoas com Albinismo, Brazil

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# FINANCIAL OVERVIEW

$46,401
RESTRICTED REVENUES

$158,277
UNRESTRICTED REVENUES

TOTAL REVENUES $204,678

TOTAL EXPENDITURES $191,575

$152,575
PROGRAMMING

$20,756
SUPPORT

$29,899
AWARENESS, OUTREACH & ADVOCACY

$22,633
ISCA & RESEARCH

$9,615 IAAD

$38,688
MEMBERSHIP MEETINGS

$30,984
WORLD FORUM ON SKIN CANCER

$5,708 FUNDRAISING

$33,289
MANAGEMENT & GENERAL

$13,106 NET OPERATING INCOME



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# OUR PARTNERS

ILDS & IFD

STANDING VOICE

EADV

GENESPOIR

WORLD SKIN HEALTH COALITION

FONDATION PIERRE FABRE

GLOBALSKIN

HPS NETWORK

ERN SKIN

VISION OF CHILDREN FOUNDATION

RARE DISEASES INTERNATIONAL

UN MANDATE ON THE ENJOYMENT OF HUMAN RIGHTS BY PERSONS WITH ALBINISM

CLINGEN

VISION FOR TOMORROW FOUNDATION

NOAH

ISHR

FONDATION VOIR & ENTENDRE
INSTITUT FORESIGHT

INTERNATIONAL AGENCY FOR RESEARCH ON CANCER



THE GLOBAL ALBINISM ALLIANCE — ANNUAL REPORT 2025

# SCIENTISTS WE PARTNER WITH

## ASIA

TAMIO SUZUKI
Yamagata University, Yamagata, Japan

WEI LI
Beijing Children's Hospital, Beijing, China

VINILA SWARMY
Fiji Albinism Project, Suva, Fiji

## MIDDLE EAST

ANAT BLUMENFELD
Hadassah University Medical Center
Jerusalem, Israel

CLAUDIA YAHALOM
Hadassah University Medical Center
Jerusalem, Israel

## LATIN AMERICA

CAROLINA MARÇON
Santa Casa de Misericordia Hospital in São Paulo, São Paulo, Brazil

## NORTH AMERICA

BRIAN BROOKS
National Eye Institute, Bethesda, MD, USA

DAVID ADAMS
National Human Genome Research Institute (NHGRI), Bethesda, MD, USA

STACIE LOFTUS
National Human Genome Research Institute (NHGRI) Bethesda, MD, USA

ELENA OANCEA
Brown University, Providence, RI, USA

JONATHAN ZIPPIN
Weill Cornell Medicine, New York City, NY, USA

MICHAEL MARKS
Children's Hospital of Philadelphia (CHOP)
Philadelphia, PA, USA

JOSEPH CARROLL
Medical College of Wisconsin
Milwaukee, WI, USA

WILLIAM OETTING
University of Minnesota, Minneapolis, MN, USA

ESTHER FREEMAN
Center for Global Health, Massachusetts General Hospital, ILDS Board Member, GLODERM, Boston, USA

HENRY LIM
ILDS President, Detroit, USA

## EUROPE

BENOIT ARVEILER
Bordeaux University Hospital, Bordeau, France

FANNY MORICE-PICARD
Bordeaux University Hospital, Bordeau, France

MATHIEU FIORE
Bordeaux University Hospital, Bordeau, France

SMAIL HADJ-RABIA
Hopital Necker-Enfants Malades
Institut Imagine, Paris, France

ALEXANDRA REBSAM
Institut de la Vision, Paris, France

KAREN GRØNSKOV
University of Copenhagen
Copenhagen, Denmark

MARIA VAN GENDEREN
University Medical Center Utrecht
Utrecht, Netherlands

PANAGIOTIS SERGOUNIOTIS
Manchester Royal Eye Hospital
Manchester Centre for Genomic Medicine
University of Manchester
Manchester, UK

# SCIENTISTS WE PARTNER WITH

MERVYN THOMAS
University of Leicester, Leicester, UK

MICHAEL HOFFMAN
University Eye Clinic, Magdeburg, Germany

VALERIE MCCORMACK
IARC, Lyon, France

ANDREW SHARP
University Hospitals of Leicester, Leicester, UK

CHRISTOPHE PRZYBYLSKI
Fondation Pierre Fabre, Lavaur, France

CLAIRE FULLER
London Bridge Hospital, ILDS Board Member, IFD Chair, London, UK

GISELA HEBE PETITI
Hospital Moisés Broggi, Dermalawi, Barcelona, Spain

KETTY PERRIS
Università dell'Aquila, ILDS Board Member, Rome, Italy

MATTHIAS MÖHRLE
University of Tuebingen, Tübingen, Germany

MAFALDA SOTO
Beyond Suncare, Madrid, Spain

MARIA-JESUS TORRES
Africa Directo, Barcelona, Spain

YOLANDA GILABERTE
ASDV, Zaragoza, Spain

## AFRICA

DAUDI MAVURA
RDTC, Moshi, Tanzania

DORIANE SABUSHIMIKE
Kamenge Military Hospital, Bujumbura, Burundi

NCOZA DLOVA
University of Kwazulu-Natal, ILDS Board Member, Durban, South Africa

OUSMANE FAYE
RDTC, Bamako, Mali

RASHMI SARKAR
Indian Association of Dermatologists Venerelogists and Leprologists, New Delhi, India
ILDS Board Member

TENGANAWO MZUMALA ESTHER
Kamuzu Central Hospital/Queen Elizabeth Hospital, Lilongwe, Malawi

KELVIN MPONDA
Kamuzu Central Hospital/Queen Elizabeth Hospital, Lilongwe, Malawi



THE GLOBAL ALBINISM ALLIANCE —— ANNUAL REPORT 2025

# OVERVIEW OF ALBINISM ORGANIZATIONS

## ASIA

CHINESE ORGANIZATION FOR ALBINISM

JEEVAN TRUST

SAHKAR CHARITABLE TRUST

CENTRAL INDIA ALBINISM SOCIETY

ALBINO INDONESIA FAMILY

KOMUNITAS ALBINO INDONESIA / ALBINISM COMMUNITY OF INDONESIA

JAPANESE ALBINISM NETWORK

KUALA LUMPUR AND SELANGOR ALBINISM ASSOCIATION

NATIONAL DISABLED ALBINO NEPAL

PAKISTAN ALBINISM SOCIETY

ALBINISM PHILIPPINES

TAIWAN ALBINO CARING ASSOCIATION

BẠCH GIA TRANG

INDIAN ALBINISM FOUNDATION

## MIDDLE EAST

IRAN ALBINISM ASSOCIATION

ALBI - ALBINISM ASSOCIATION OF ISRAEL

ALBINO JORDAN

ALBINIZM DERNEGI

## NORTH AMERICA

BORN TOO WHITE OTTAWA

NOAH – NATIONAL ORGANIZATION FOR ALBINISM AND HYPOPIGMENTATION

HERMANSKY-PUDLAK SYNDROME NETWORK

THE ASSOCIATION OF AFRICAN AMERICAN ALBINISM AWARENESS LTD

VISION FOR TOMORROW FOUNDATION

THE ALBINISM ALLIANCE GROUP

FONDATION ALBHA

ALBINO FOUNDATION OF TRINIDAD AND TOBAGO

VISION OF CHILDREN FOUNDATION

## LATIN AMERICA

ALBINISMO ARGENTINA

FUNDACIÓN NACIONAL DE ALBINISMO SIMPLEMENTE AMIGOS

ALBINOS DE MENDOZA

ALBINOS DE MISIONES

ALBINOS PATAGONIA

ALBINOS ZONA SUR

AMIGOS ALBINOS DE CÓRDOBA

BUENOS AIRES - SIMPLEMENTE AMIGOS

ORGANIZACIÓN LATINOAMERICANA DE ALBINISMO

ALBINISMO SEM FRONTEIRAS

ALBINOS DO MEU BRASIL E DO MUNDO

ALBINOS ES

ALBINOS(AS) DO NOSSO NORDESTE

ASSOCIAÇÃO DAS PESSOAS COM ALBINISMO EM MATO GROSSO

ASSOCIAÇAO DOS ALBINOS DE ALAGOAS

INSTITUTO NÓBREGA

UNIVERSIDADE FEDERAL DO RIO DE JANEIRO (UFRJ) - PROJETO DE EXTENSÃO UNIVERSITÁRIA

ASSOCIAÇÃO DAS PESSOAS COM ALBINISMO NA BAHIA

CORPORACIÓN ALBINOS CHILE

ALBINOS DE CORAZÓN

FUNDACIÓN ALBINOS POR COLOMBIA

FUNDACIÓN VIVE FELIZ

COMUNIDAD DE PERSONAS CON LA CONDICIÓN DE ALBINISMO EN ORIENTE CUBA

COMUNIDAD ALBINA SANTO DOMINGO DE LOS TSÀCHILAS

FUNDACIÓN DE ALBINOS PIEL DE ÁNGEL

ORGANIZACIÓN NACIONAL DE ALBINISMO DEL ECUADOR

ALBINOS DE GUATEMALA

UNION GUATEMALTECA DE ALBINISMO

ALBIN GIRL

ALBINO LATINO

FUNDACIÓN PIEL DE LUNA ALBINOS DE MÉXICO A.C.

FUNDACIÓN BENÉFICA SOS ALBINOS PANAMÁ

ALBINOS PARAGUAY

ALBINOS PERÚ

ALBINOS DEL URUGUAY

ALBINOS DE VENEZUELA

ALSOA

UNIÓN LATINOAMERICANA DE ALBINISMO

## EUROPE

NOAH ALBINISMUS SELBSTHILFEGRUPPE E.V

LIGUE POUR LA DÉFENSE DES ALBINOS

ALBINISM EUROPE

GENESPOIR

ALBINA

DANSK FORENING FOR ALBINISME

SUOMEN ALBINISMIYHDISTYS RY

ALBINISM FELLOWSHIP UK & IRELAND

ALBINISMO.EU

ALBINIT

ASSOCIATION OMBRE ET LUMIÈRE MONACO

NORSK FORENING FOR ALBINISME

STOWARZYSZENIE NA RZECZ OSÓB Z ALBINIZMEM W POLSCE

COMUNITATEA ALBINISM ROMANIA INTERNATIONALA

RUSSIAN COORDINATING SUPPORT CENTRE FOR PATIENTS WITH ALBINISM

ALBA

OOGVERENIGING ALBINISME

SVENSKAR MED ALBINISM! | ALBINISM SVERIGE

SOLIDARITÉ POUR ALBINISME SUISSE

## OCEANIA & PACIFIC

ALBINISM FELLOWSHIP OF AUSTRALIA

HEALTHY SKIN FIJI

PARENTS OF CHILDREN WITH ALBINISM FIJI

FIJI ALBINISM PROJECT

ALBINISM TRUST

CLARENCE SEBASTIAN FOUNDATION



THE GLOBAL ALBINISM ALLIANCE —— ANNUAL REPORT 2025

# OVERVIEW OF ALBINISM ORGANIZATIONS

## AFRICA

ALDEIA NISSI

ASSOCIAÇÃO DE APOIO A PESSOAS ALBINAS DO CUNENE

ASSOCIAÇÃO DE APOIO DE ALBINOS DE ANGOLA

FRATERNIDADE ALBINISTA

GRUPO TEATRAL EXCESSO DE COR

GRUPO VOLUNTÁRIO DE APOIO A PESSOAS COM ALBINISMO EM ANGOLA

LIGA ANGOLANA PARA A DEFESA DOS ALBINOS

ASSOCIATION ALGÉRIENNE D'ALBINISME

ASSOCIATION MAROCAINE DES ALBINOS

MOVIMENTO PRO ALBINO EM ANGOLA

TSHIMOLOGO ASSOCIATION FOR ALBINISM

ALBINISM SOCIETY OF BOTSWANA

UNDER THE SAME SUN

ALBINISM SOCIETY OF ESWATINI

MINERVA - ALBINISM IN ESWATINI

STUKIE MOTSA FOUNDATION

SWAZILAND ASSOCIATION OF PERSONS WITH ALBINISM

VITILIGO AND ALBINISM ASSOCIATION

ALBINISM FOUNDATION OF EAST AFRICA

DR CHOKSEY ALBINISM FOUNDATION

KENYA ALBINO CHILD SUPPORT

KISII ALBINISM SUPPORT ORGANIZATION

KWALE ALBINISM GROUP

POSITIVE EXPOSURE KENYA

THE ALBINISM EMPOWERMENT NETWORK

BLACK ALBINISM

EMPOWERED ALBINISM GROUP

ALBINISM SOCIETY OF KENYA

ALBINISME MADAGASCAR

ASSOCIATION OF PERSONS WITH ALBINISM IN MALAWI

STANDING VOICE

KANIMAMBO - ASSOCIAÇÃO DE APOIO AO ALBINISMO

AMOR A VIDA

ASSOCIAÇÃO DE APOIO A ALBINOS DE MOÇAMBIQUE

ASSOCIAÇÃO ZE MANUEL PINTO

THE SHADE TREE PROJECT

NAMIBIAN ALBINO ASSOCIATION

SUPPORT IN NAMIBIA OF ALBINISM SUFFERERS REQUIRING ASSISTANCE

APHAD - ALIKAR CENTER FOR PEACE, HUMAN RIGHTS AND DEMOCRACY

SOMALI ALBINISM EMPOWERMENT ORGANIZATION

ALBINISM SOCIETY IN LIMPOPO

A BEAUX ALBINISM BEAUTY

ALBINISM ADVOCACY FOR ACCESS

ALBINISM RENAISSANCE

ALBINISM SOCIETY OF KWA ZULU NATAL

ALBINISM SOCIETY OF SOUTH AFRICA

BEAUTY BY NATURE ALBINISM SOCIETY

CHILDLINE SA

EASTERN CAPE ALBINISM SOCIETY SOUTH AFRICA

HUMAN RIGHTS MEDIA CENTER

IBUTHO LEZWE FOUNDATION

KWATSADUZA ALBINISM SOCIETY INITIATIVE

WESTERN CAPE ALBINISM AND HYPO-PIGMENTATION FOUNDATION

KHULISA SOCIAL SOLUTIONS

ALBINO PEACEMAKERS

GOLDEN AYA TANZANIA ORGANIZATION

GOOD HOPE STAR FOUNDATION

PROMOTION OF EDUCATION LINK ORGANIZATION

STICHTING INSIDE THE SAME

ALBINOS TANZANIA DEVELOPMENT FOUNDATION

ALL ABOUT ALBINISM CAMPAIGN ASSOCIATION

BRIGITTE ALFRED FOUNDATION

SMA LAY ASSOCIATION ALBINO SUPPORT PROJECT

TANZANIA ALBINO ECONOMIC AND HEALTH ORGANIZATION

TANZANIA ALBINISM SOCIETY

THE KESHO TRUST

SHADE

JOSEPHAT TORNER FOUNDATION EUROPE

ASANTE MARIAMU

AFRICA ALBINO FOUNDATION UGANDA

ALBINISM CRISIS OUTREACH

ASANTE ALBINO ASSOCIATION

LIRA DISTRICT ALBINO ASSOCIATION (LANGO SUB REGION)

LUWERO DISTRICT ALBINO ASSOCIATION

NAZIGO ALBINO ASSOCIATION (KAYUNGA)

NORTHERN UGANDA ALBINO ASSOCATION (NORTHERN UGANDA AND WEST NILE)

SITE FOR COMMUNITY SERVICES PROGRAMME

SOURCE OF THE NILE UNION OF PEOPLE WITH ALBINISM (NATIONWIDE COVERAGE)

TUSIMAME AFRICAN ALBINISM FOUNDATION

UGANDA ALBINISM AID PROJECT

ALBINISM UMBRELLA

EVERY CHILD MINISTRIES

GLOBAL AID MISSION

ALBINO FOUNDATION OF ZAMBIA

NATIONAL ALBINISM INITIATIVE NETWORKING OF ZAMBIA

ZAMBIAN ALBINISM MATTERS ORGANIZATION

ALBINISM MULTIPURPOSE COOPERATIVE

ALBINO GLOBAL FOUNDATION

ALBINO TRUST ZIMBABWE ONLINE

MISS ALBINISM ZIMBABWE TRUST

PRINCESS SAFETY CENTRE FOUNDATION

ALBINISM ALIVE INITIATIVE

ZIMBABWE ALBINO ASSOCIATION

ALBINO CHARITY ORGANISATION OF ZIMBABWE

AFRICA ALBINISM NETWORK

AFRICAN UNION FOR PERSONS WITH ALBINISM

ALBINOS SANS FRONTIERES

ASSOCIATION JHONY CHANCEL POUR LES ALBINOS

ASBL INTERNATIONALE VROUWEN

ASSOCIATION "ALBINOS CRÉATURES HUMAINES À PART ENTIÈRE"

ASSOCIATION POUR LA PROTECTION ET LA PROMOTION DES ALBINOS "ENTRE NOUS"

ASSOCIATION ARTISTIQUE ET CULTURELLE DES PERSONNES ALBINOS - BÉNIN

DIVINE CONNECTION WORLDWIDE

ONG VALEUR ALBINOS

FÉDÉRATION DES ASSOCIATIONS DE PERSONNES VIVANT AVEC L'ALBINISME EN AFRIQUE DE L'OUEST

ASSOCIATION ALBI INTERNATIONAL

ASSOCIATION BURKINABE POUR L'INTEGRATION DES PERSONNES ALBINOS

ASSOCIATION DES FEMMES ALBINOS DU BURKINA

ASSOCIATION POUR LA PROTECTION ET LA PROMOTION DES ALBINOS

ASSOCIATION SIMA

SOLIDARITÉ POUR L'INSERTION DES ALBINOS DU MALI

ASSOCIATION DES FEMMES ALBINOS ESPOIR DU BURUNDI

LIVE TOGETHER AS FAMILY

ORGANISATION DES PERSONNES ALBINOS DU BURUNDI

AFRICAN ALBINISM AMBASSADORS

AMICALE DES FEMMES ALBIBELLES

ASSOCIATION OF HANDICAPPED ALBINO YOUTHS OF CAMEROON AND AFRICA



THE GLOBAL ALBINISM ALLIANCE —— ANNUAL REPORT 2025

# OVERVIEW OF ALBINISM ORGANIZATIONS

ASSOCIATION FEMMES ALBINOS DU CAMEROUN

ASSOCIATION DE PARTAGE ET D'ENTRAIDE DES ALBINOS DU CAMEROUN

ASSOCIATION NATIONALE DE PROMOTION ET DE PROTECTION DES DROITS DE L'HOMME

ASSOCIATION FOCUS

ASSOCIATION POUR LA PROMOTION DES ALBINOS AU CAMEROUN

MR & MRS ALBINOS CAMEROUN

VILLAGE D'ENFANTS ALBINOS DU CAMEROUN

ASSOCIATION MONDIALE POUR LA DEFENSE DES INTERETS ET LA SOLIDARITE DES ALBINOS

RÉSEAU DES ORGANISATIONS DES PERSONNES VIVANT AVEC ALBINISME D'AFRIQUE CENTRALE

ALBICARE INTERNATIONAL

ASSOCIATION NATIONALE DES ALBINOS DE CENTRAFRIQUE

ASSOCIATION D'APPUI AUX ALBINOS DU TCHAD

COMITÉ MISS ALBINOS

FONDATION SALIF KEITA

ACTION POUR L'ALBINOS (KASAI ORIENTAL)

ALBISO

ASBL PLUS DE COULEURS - FIÈREMENT NDUNDU

ASSOCIATION DES ALBINOS DU SANKURU

ASSOCIATION DES ALBINOS ET HANDICAPÉS DU KASAÏ CENTRAL

ASSOCIATION FAMILLE D'ACTION MULTIFORME- COMMUNAUTÉ NATIONALE DES PERSONNES ATTEINTES D'ALBINISME

ASSOCIATION POUR LA PROTECTION ET LE DEVELOPPEMENT DE LA PERSONNE ALBINOS

CORBETTA ONG

FONDATION JULIO LEVOTRE

FONDATION PAULINE ALBINOS

LES AMIS DE DEPHILL POUR LA SENSIBILISATION À L'ALBINISME

ONG DES ALBINOS FONDATION MWINMBA TEXAS

ORGANISATION DES PERSONNES ENGANGEES POUR LA CAUSE DES ALBINOS

ORGANISATION POUR LE BIEN ETRE DES ALBINOS AU CONGO

PARLEMENT DES FEMMES ALBINOS AU SUD-KIVU

PROMOTION ET PROTECTION DES ALBINOS DU KASAÏ

SOLIDARITÉ DES ALBINOS DU KASAÏ ORIENTAL

VOICE OF ALBINO ONG

HOPE OF ALBINISM

ASSOCIATION COMPASSION ALBINOS

AGIR POUR LA CAUSE DES ALBINOS RDC - (GOMA, NORD KIVU)

ASSOCIATION DE LUTTE POUR LE BIEN-ETRE DES ALBINOS

ASSOCIATION OF GAMBIAN ALBINOS

ASSOCIATION NATIONALE DES ALBINOS DU SÉNÉGAL

ENGAGE NOW AFRICA

GHANA ASSOCIATION OF PERSONS WITH ALBINISM

CONFEDERATION NATIONALE DES ALBINOS DE GUINÉE

UNION POUR LE BIEN ETRE DES ALBINOS DE GUINÉE

FONDATION POUR LE SECOURS ET L'INTEGRATION SOCIALE DES ALBINOS

ASSOCIACAO DOS ALBINOS DA GUINEA-BISSAU

ACTION ET SOLIDARITÉ POUR LES ALBINOS DE CÔTE D'IVOIRE

ASSOCIATION IVOIRIENNE POUR LA PROMOTION DES FEMMES ALBINOS

ASSOCIATION NATIONALE DES ALBINOS DE CÔTE D'IVOIRE

ASSOCIATION POUR LE BIEN-ÊTRE DES ALBINOS DE BOUAKÉ

ONG BIEN ÊTRE DES ALBINOS DE CÔTE D'IVOIRE

FÉDÉRATION DES ASSOCIATIONS POUR LE BIEN-ÊTRE DES PERSONNES ALBINOS DE CÔTE D'IVOIRE

LIBERIA ALBINISM SOCIETY

STAND-UP STAND-OUT ALBINISM FOUNDATION

UNITED ALBINOS ASSOCIATION OF LIBERIA

ASSOCIATION MALIENNE POUR LA DÉFENSE DES DROITS ET LE BIEN-ÊTRE DES ALBINOS

ASSOCIATION MALIENNE POUR LA PROTECTION DES ALBINOS

ASSOCIATION MALIENNE POUR LA SENSIBILISATION, LA PROMOTION ET LA PROTECTION DES PERSONNES VIVANTES AVEC ALBINISME - SOS ALBINOS

COALITION DES ORGANISATIONS DE PERSONNES ATTEINTES D'ALBINISME

THE SALIF KEITA GLOBAL FOUNDATION

ORGANISATION MAURITANIENNE POUR L'APPUI ET L'INSERTION DES ALBINOS

ASSOCIATION NATIONALE DES ALBINOS DU NIGER

ANAMBRA STATE ALBINISM ASSOCIATION

THE ALBINISM NETWORK ASSOCIATION

ONOME AKINLOLU MAJARO FOUNDATION

WHITE ANGELS FOUNDATION

THE ALBINO FOUNDATION

ORGANIZATION FOR INTEGRATION AND PROMOTION OF PEOPLE WITH ALBINISM

RWANDA ALBINISM SOCIETY

ALLIANCE NATIONALE POUR LA PROMOTION ET LA RÉINSERTION DES ALBINOS AU SÉNÉGAL

CLUB ALBINOS SN

FÉDÉRATION NATIONALE DES ALBINOS SÉNÉGAL

AROBAZ ALBINISME AU SÉNÉGAL

CARE ALBINOS

ALBINISM ROYAL FOUNDATION SIERRA LEONE

SIERRA LEONE ALBINISM FOUNDATION

SIERRA LEONE ASSOCIATION FOR PERSONS WITH ALBINISM

GOLDEN SHADE

ASSOCIATION INITIATIVE PRO.TO.P.A

ASSOCIATION NATIONALE DES PERSONNES ATTEINTES D'ALBINISME AU TOGO

CAS SOCIAL ALBINOS ENFANTS ADULTES

LES ALBINOS DE HEMA NAYÉLÉ À BANFORA

AISBL ECRAN TOTAL

ANIDA ENSEMBLE CHANGEONS LE REGARD SUR L'ALBINISME

ALBINISM INCLUSION AND EQUALITY ORGANIZATION

CENTRE CANADIEN DE SENSIBILISATION À L'AMÉLANISME

BEYOND SUNCARE

ENGAGE NOW AFRICA

FONDATION PIERRE FABRE

SARAH'S VOICE

VOICE OF ALBINISM

SAINT LUDOVIK INSTITUTE OF CHARITY

ONG ALBINOSGE

LUMINA FOUNDATION FOR PERSONS WITH ALBINISM

NORTHERN ALBINISM FORUM

ALBINISM SOCIETY OF KWAZULU-NATAL

NASARAWA STATE ASSOCIATION OF PERSONS WITH ALBINISM NAPWA

LYAKIREMA INITIATIVE FOR PERSONS WITH ALBINISM

ALBINISM BROTHERHOOD

WELL-BEING OF PEOPLE LIVING WITH ALBINISM (ABEPA)



THE GLOBAL ALBINISM ALLIANCE —— ANNUAL REPORT 2025

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