

A close-up, high-contrast portrait of a person with albinism. The individual has light-colored skin, sparse light-colored hair, and light-colored eyes. The image is framed by large, white, bold letters spelling out 'ISCA' vertically on the left and 'PA' vertically on the right.

ISCA²⁵

CONFERENCE IMPACT REPORT





ISCA is THE meeting point worldwide for all scientists interested in sharing and improving knowledge of the biomedical aspects of albinism and, more generally, improving the health of those with albinism. It builds on the momentum created in 2012 with the launch of the EDA (European Days of Albinism) conference series that evolved into ISCA.

ISCA 2025 was organized with the guidance of a prestigious Scientific Advisory Committee, consisting of 16 internationally recognized researchers and clinicians from different fields of science and different regions of the world.

By holding ISCA, the Global Albinism Alliance is providing a place where health care providers, researchers, and albinism organization leaders can meet, share ideas and experiences and discuss strategies to advance the knowledge of albinism in order to tackle the health challenges faced by persons with albinism in all regions of the world.

The Global Albinism Alliance believes in the power of being united in order to improve the quality of life of those with albinism in a holistic manner.

188
Attendees in 2025

13+
hours of albinism-focused
scientific sessions

43
oral presentations
and 16 posters

PROGRAM AT A GLANCE

ISCA 25 —— DATA, METRICS AND SURVEY RESULTS

TUESDAY
21 JANUARY

WEDNESDAY
22 JANUARY

THURSDAY
23 JANUARY

FRIDAY
24 JANUARY

WEDNESDAY
17 DECEMBER

POSTER EXHIBITION
ACCESIBLE AT ANY TIME

LIVE SESSIONS

Additional
ISCA
Session

Genetics

Genotype-
Phenotype
Correlations
& Cell Biology

Visual function
& pathophysiology,
Rehabilitation &
Therapies

Albinism in low
and middle-resource
tropical settings
Skin Cancer & Health
Management

Social Time

Live Poster Session

ISCA 2025
Virtual Cocktail



DETAILED
PROGRAM
OF THE MAIN
SESSIONS



LIST OF
POSTERS



ADDITIONAL SESSION
PROGRAM

ISCA 25 —— DATA, METRICS AND SURVEY RESULTS

SPEAKERS

Stephanie ACKER (Grenach Wyhlen, Germany)
 David R ADAMS (Bethesda, MD, USA)
 Donna APPELL (Oyster Bay, NY, USA)
 Duarte BARRAL (Lisbon, Portugal)
 Bary BIGAY MERCEDES (Dominican Republic)
 Malanna BIGMA (Lomé Togo)
 Karen BLY (Sandy Lake, PA, USA)
 Prabha CHOKSEY (Nairobi, Kenya)
 Olufolakemi COLE-ADEIFE (Lagos, Nigeria)
 Cécile COURDIER (Bordeaux, France)
 Cédric DELEVOYE (Paris, France)
 Modibo DIALLO (Bordeaux, France)
 Aman GEORGE (Bethesda, MA, USA)
 Karen GRØNSKOV (Copenhagen, Denmark)
 Paige HELMER (New York, NY, USA)
 Michael B. HOFFMANN (Magdeburg, Germany)
 Charles HUSS (Dunbar, WV, USA)
 Gaylord INENA WA INENA (Kisangani, DRC)
 Sophie JAVERZAT (Bordeaux, France)
 Herbert KIRCHESCH (Cologne, Germany)
 Charlotte KRUIJT (Zeist, The Netherlands)
 Stacie LOFTUS (Bethesda, MD, USA)
 Shushu LV (Beijing, China)

Brice MAGNE (Philadelphia, PA, USA)
 Effrosyni MANALI (Athens, Greece)
 Carol MASON (New York, NY, USA)
 Valerie MCCORMACK (Lyon, France)
 Vincent MICHAUD (Bordeaux, France)
 Lluis MONTOLIU (Madrid, Spain)
 Shirley PARRAGA (Winston-Salem, NC, USA)
 Ninsiima PHIONAH (Kampala, Uganda)
 Alexandra REBSAM (Paris, France)
 Nicole ROSS (Boston, MA, USA)
 Waleed SABIR (Bethesda, MD, USA)
 Doriane SABUSHIMIKE (Bujumbura, Burundi)
 Panos SERGOUNIOTIS (Manchester, UK)
 Or SHMUELI (Jerusalem, Israel)
 Sarah TOAY (Bethesda, MD, USA)
 Caterina TRAMONTANA (Pavia, Italy)
 Yuhong Anna WANG (Bethesda, MA, USA)
 Yizhen WANG (Beijing, China)
 Tyler WILLS (New York, NY, USA)
 Jonathan ZIPPIN (New York, NY, USA)

POSTER PRESENTERS

Chloe ADAMS (Bethesda, MA, USA)
 Paulyana CORECCO-MOURA (Porto Alegre, Rio Grande do Sul, Brazil)
 Alicia DEFAY-STINAT (Bordeaux, France)
 Modibo DIALLO (Bordeaux, France)
 Rebecca DONADONI (Genoa, Italy)
 Hugo FOURNIER (Bordeaux, France)
 Jamila GHARIB (Zanzibar, Tanzania)
 Sofya IONOVA (Moscow, Russia Federation)
 Zibing JIN (Beijing, China)
 Pierre KITHA (Lubumbashi, DRC)
 Roberto MAZZETTO (Padua, Italy)
 Yannick MUKENDI NKESU (Mbujimayi, DRC)
 Elizabeth ROBERTS (Leicester, UK)
 Eila van STIPRIAAN (Amsterdam, The Netherlands)
 Vinila SWAMY (Suva, Fiji)
 Yingzi ZHANG (Beijing, China)

All speakers and poster presenters for ISCA 2025 have been selected through a Call for Abstracts.



CALL FOR ABSTRACTS 

SCIENTIFIC ADVISORY COMMITTEE

ISCA 2025 was organized with the support of an international Scientific Advisory Committee made up of the following members:

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Alexandra Rebsam
Institut de la Vision
Paris, France



Benoît Arveiler
Bordeaux University and University Hospital of Bordeaux
Bordeaux, France



Jonathan Zippin
Weill Medical College of Cornell, New York, NY, USA



Mervyn Thomas
University Hospitals of Leicester, Leicester, UK



Michael Marks
Children's Hospital of Philadelphia Research Institute and University of Pennsylvania
Philadelphia, PA, USA

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Capital Medical University
National Center for Children's Health
Beijing, China



ACCESS TO BIOS

ORGANIZER

The Global Albinism Alliance (GAA) is a non-profit organization committed to the empowerment, protection, and equal rights of individuals with albinism worldwide. Recognizing the unique challenges these individuals often face, including discrimination, marginalization, and physical harm, we work to change societal attitudes and create a world where the albinism community can thrive.

The Global Albinism Alliance's initiatives include global advocacy efforts, improving knowledge and helping albinism organizations around the world become stronger.

The Global Albinism Alliance aims to unite albinism organizations globally. It is the voice of over 250 associations of persons with albinism and other NGOs serving the albinism community in all regions of the world. These organizations operate at the local, national or international level. They all contribute to improving the lives of individuals and families affected by albinism.



SPONSORS & PARTNERS

The Global Albinism Alliance would like to express its gratitude to the following organizations whose support has made the conference possible.

Institutional partner



Organizational Support



Financial support

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ISCA2025 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 Artur Bergen.

Mervyn Thomas, Ophthalmologist, Leicester (UK)





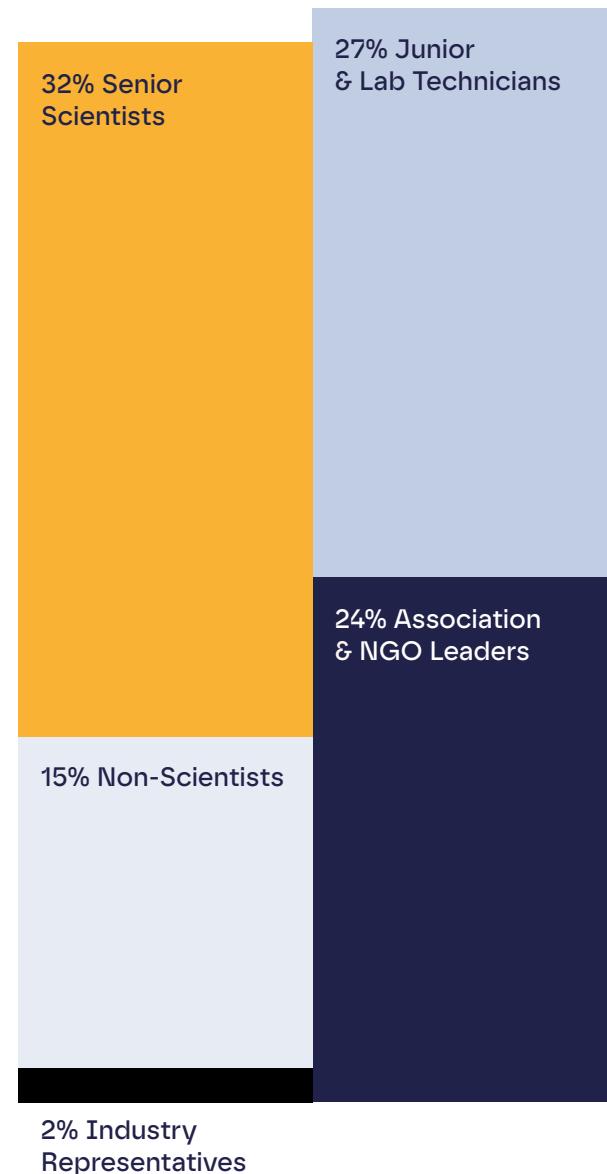
Congratulations on the ISCA event. Very very well run, and great presentations across a wide range of topics.

Andrew Sharp, Mohs Surgeon, Leicester (UK)

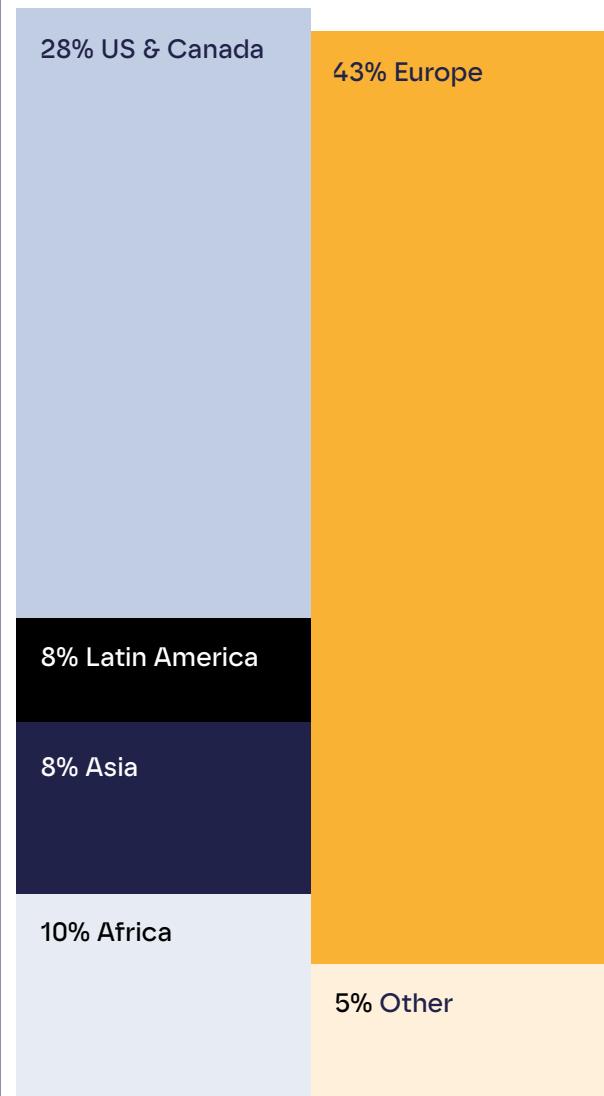
Chair of the Standing Voice Skin Cancer Advisory Committee

METRICS

PARTICIPANTS
188



FROM
45 COUNTRIES



ATTENDANCE & REPLAY

104

Average Attendees per Session

99

Replay Views Per Session Two Weeks
after the Conference

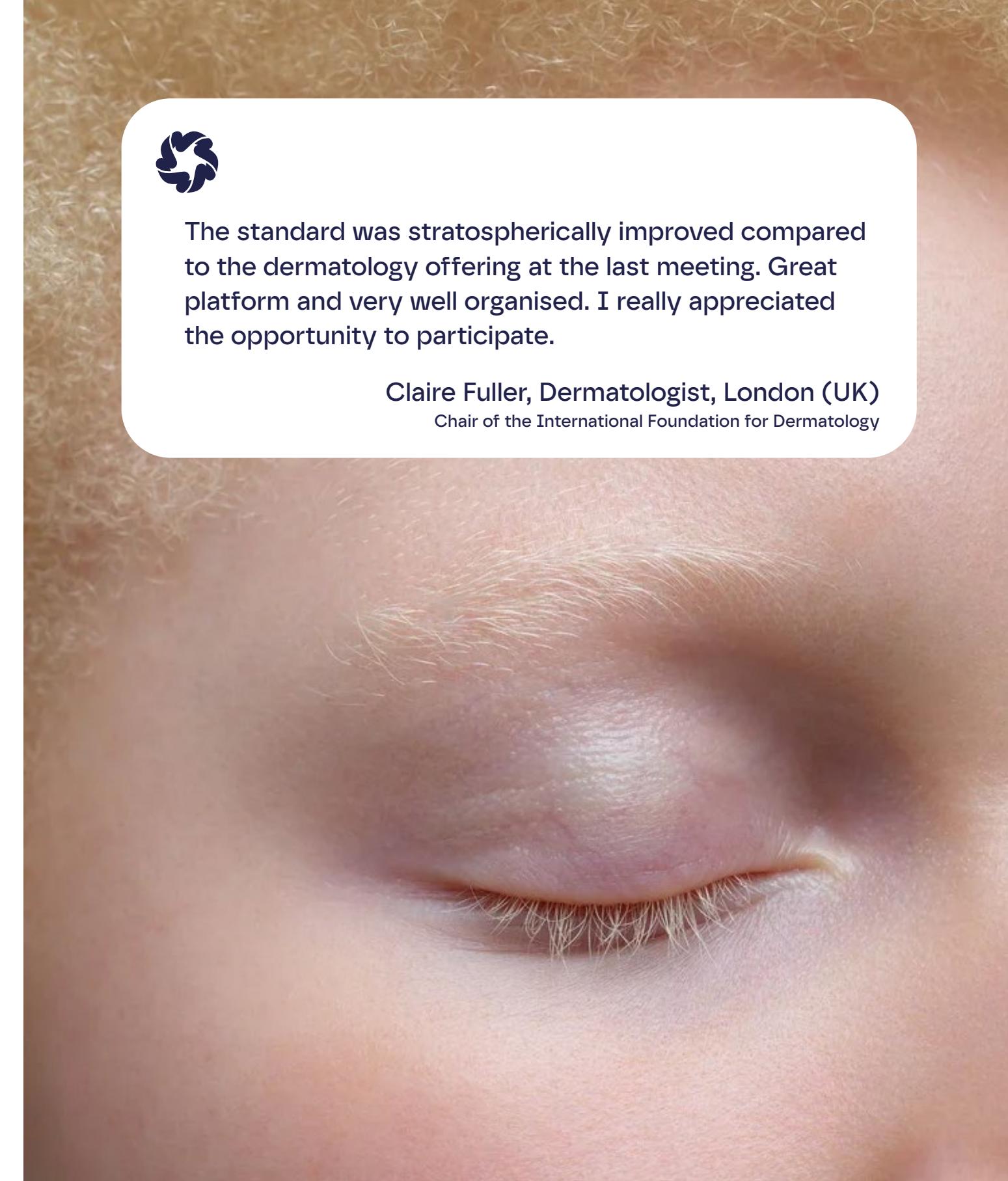
Of note: The above average number of attendees per session doesn't include
the speakers (about 9 to 12 people per session)

We lost about 12 attendees from the NIH in the last two sessions



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





What an achievement! It was outstanding! Super informative, while peppered with profound and sincere comments. Amazing job!

Donna Appell, Oyster Bay, NY (USA)
Founder and Executive Director of the HPS Network

ATTENDANCE & REPLAY

	Attendees live	Replay Views*
Genetics	129	7
Genotype-Phenotype Correlations & Cell Biology	116	165
Visual Function & Pathophysiology, Rehabilitation & Therapies	92	99
Albinism in low & middle-resource tropical settings – Skin Cancer & Health Management	79	116
Additional Session December 17	50	

*two weeks after the conference

CALL FOR ABSTRACTS, SPEAKERS & POSTERS

66

Abstracts / 50 for ISCA 2022



45

Speakers / 31 for ISCA 2022

16

Posters / 8 for ISCA 2022



SATISFACTION SURVEY RESULTS

53 Responses

49% of respondents had attended an ISCA / EDA Conference in the past

94% of respondents would consider attending a similar conference in the future.

4.6/5 Overall Satisfaction

4.8/5 Overall Satisfaction (Additional Session)

4.6/5 Satisfaction with the Program

Participant Category of Survey Respondents



SUGGESTIONS FROM PARTICIPANTS

Preferred format for next conference



SUGGESTIONS OF NEW TOPICS

- Several suggestions from both scientists and leaders of albinism organizations reflect a desire for educational sessions to complement the research-focused program, which; until now, was the main scope of ISCA.
- The ISCA program is traditionally developed primarily based on submitted abstracts, which reflect current ongoing research on albinism around the world. As a result, if no research is currently being conducted on a given topic, it cannot be included in future conferences—even if participants express interest in it.

Albinism organization leaders & non-scientists

- More on visual aids and visual rehabilitation
- Management of nystagmus
- More on aspects related to living with albinism
- Genetics, genetic testing, genetic inheritance
- X-linked ocular albinism
- Psychosocial aspects of albinism
- Therapies
- Sunscreen (Safety & Efficacy)

Scientists

- Sunscreen (formulation & local production)
- More on skin cancer
- More about the syndromic form of albinism (clinical part and disease-causing mechanisms).
- Genetic testing and its utility
- Genotype / Phenotype correlations for genetic counselling
- More about the visual characterization at the clinical level
- Nystagmus and development
- More on stem cell approaches
- More computational/AI research to study albinism
- Biochemical aspects of melanogenesis / Melanin pathway
- Studies on comorbidities (e.g. tooth malposition)
- Social Science Studies, Socio-economic aspects and psychosocial burden
- Lived Experience and patient's perspective



ISCA
25 | international
scientific
conference
on albinism