



ISCA

25

CONFERENCE IMPACT REPORT



Global
Albinism
Alliance



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

TUESDAY 21 JANUARY	WEDNESDAY 22 JANUARY	THURSDAY 23 JANUARY	FRIDAY 24 JANUARY	WEDNESDAY 17 DECEMBER
POSTER EXHIBITION ACCESIBLE AT ANY TIME				
Genetics	Genetotype– Pheotype Correlations & Cell Biology	Visual function & pathophysiology, Rehabilitation & Therapies	Albinism in low and middle-resource tropical settings Skin Cancer & Health Management	LIVE SESSIONS Additional ISCA Session
Social Time	Live Poster Session	ISCA 2025 Virtual Cocktail		



DETAILED
PROGRAM
OF THE MAIN
SESSIONS



LIST OF
POSTERS



ADDITIONAL SESSION
PROGRAM

SPEAKERS

Stephanie ACKER (Grenach Wyhlen, Germany)	Brice MAGNE (Philadelphia, PA, USA)
David R ADAMS (Bethesda, MD, USA)	Effrosyni MANALI (Athens, Greece)
Donna APPELL (Oyster Bay, NY, USA)	Carol MASON (New York, NY, USA)
Duarte BARRAL (Lisbon, Portugal)	Valerie MCCORMACK (Lyon, France)
Bary BIGAY MERCEDES (Dominican Republic)	Vincent MICHAUD (Bordeaux, France)
Malanna BIGMA (Lomé Togo)	Lluis MONTOLIU (Madrid, Spain)
Karen BLY (Sandy Lake, PA, USA)	Shirley PARRAGA (Winston-Salem, NC, USA)
Prabha CHOKSEY (Nairobi, Kenya)	Ninsiima PHIONAH (Kampala, Uganda)
Olufolakemi COLE-ADEIFE (Lagos, Nigeria)	Alexandra REBSAM (Paris, France)
Cécile COURDIER (Bordeaux, France)	Nicole ROSS (Boston, MA, USA)
Cédric DELEVOYE (Paris, France)	Waleed SABIR (Bethesda, MD, USA)
Modibo DIALLO (Bordeaux, France)	Doriane SABUSHIMIKE (Bujumbura, Burundi)
Aman GEORGE (Bethesda, MA, USA)	Panos SERGOUNIOTIS (Manchester, UK)
Karen GRØNSKOV (Copenhagen, Denmark)	Or SHMUELI (Jerusalem, Israel)
Paige HELMER (New York, NY, USA)	Sarah TOAY (Bethesda, MD, USA)
Michael B. HOFFMANN (Magdeburg, Germany)	Caterina TRAMONTANA (Pavia, Italy)
Charles HUSS (Dunbar, WV, USA)	Yuhong Anna WANG (Bethesda, MA, USA)
Gaylord INENA WA INENA (Kisangani, DRC)	Yizhen WANG (Beijing, China)
Sophie JAVERZAT (Bordeaux, France)	Tyler WILLS (New York, NY, USA)
Herbert KIRCHESCH (Cologne, Germany)	Jonathan ZIPPIN (New York, NY, USA)
Charlotte KRUIJT (Zeist, The Netherlands)	
Stacie LOFTUS (Bethesda, MD, USA)	
Shushu LV (Beijing, China)	

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:

EXECUTIVE BOARD



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

COMMITTEE MEMBERS



Brian Brooks
National Eye Institute, NIH
Bethesda, MD, USA



Fanny Morice-Picard
University Hospital of
Bordeaux, Bordeaux, France



David Adams
National Human Genome
Research Institute, NIH
Bethesda, MD, USA



Joseph Carroll
Medical College of Wisconsin
Milwaukee, WI, USA



Karen Grønskov
Kennedy Center,
Rigshospitalet
Copenhagen, Denmark



Maria van Genderen
Bartimeus, Diagnostic Centre
for Rare Visual Disorders
Zeist, The Netherlands



Mathieu Fiore
University Hospital of
Bordeaux
Bordeaux, France



Michael Hoffmann
University Eye Clinic
Magdeburg, Germany



Panagiotis Sergouniotis
Manchester Royal Eye
Hospital, Manchester Centre
for Genomic Medicine
University of Manchester
Manchester, UK



Tamio Suzuki
Yamagata University
Yamagata, Japan



Wei Li
Beijing Children's Hospital
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

PLATINUM SPONSOR



GOLD SPONSOR



SILVER SPONSOR



BRONZE SPONSOR



SPONSOR



International Alliance of Dermatology Patient Organizations



DETAILS HERE



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 par 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



Very good conference, very well organized. Very nice that we had participation from so many countries. The speakers were good – I was very impressed with the talks. I think the sessions were well chosen. And it worked well with chairing the sessions.

Karen Grønskov, Geneticist, Copenhagen (Denmark)

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.

Participant Category of Survey Respondents



4.6/5 Overall Satisfaction

4.8/5 Overall Satisfaction (Additional Session)

4.6/5 Satisfaction with the Program

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 commorbidities (e.g. tooth malposition)
- Social Science Studies, Socio-economic aspects and psychosocial burden
- Lived Experience and patient’s perspective



Global
Albinism
Alliance

ISCA
25

international
scientific
conference
on albinism