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# **Forward**

2024 marked a pivotal year for the Africa Albinism Network (AAN)—a year of reflection, renewed purpose, and transition.

As we commemorated the 10th anniversary of International Albinism Awareness Day (IAAD), we found ourselves standing on a foundation laid by years of unwavering advocacy and groundbreaking achievements. The journey has been one of courage, community, and commitment. From joining forces to launch a petition to re-add sunscreen to the World Health Organization's essential medicines list to hosting the first-ever Women's Learning Forum for women with albinism in Nairobi, AAN continued to push the boundaries of possibility and inclusion.

This year also marked a profound shift in leadership. We bid farewell to our founder and Executive Director, Ikponwosa "I.K." Ero, whose vision gave life to the network and galvanized a continental movement. Her legacy will remain embedded in the DNA of AAN. As we welcomed Bonface Massah to the helm, we embraced not only a new chapter but also a renewed momentum. With over 15 years of advocacy experience and an unshakeable commitment to justice, Bonface brings a wealth of expertise that will help guide AAN's strategic growth in the years ahead.

At the heart of our 2024 accomplishments lies the collective strength of regional, national, and global partnerships across academia, civil society, and the media. Together, we submitted joint human rights reports, supported national policy advancements such as Tanzania's National Action Plan, amplified the voices of women with albinism, and promoted continued understanding of the intersection between climate justice and the lived experiences of persons with albinism. Finally, we strengthened the governance, transforming the AAN Advisory Board into a full and accountable Governing Board.

This report reflects not only what we have achieved but also charts the path forward. In 2025, we embark on a new strategic direction grounded in five foundational pillars, aimed at deepening impact, strengthening collaboration, and ensuring the long-term sustainability of our mission.

We extend our deepest gratitude to our partners, supporters, and the resilient albinism communities across the world and particularly in Africa. Your voices, stories, and actions inspire us to keep going—toward a continent where dignity, safety, and inclusion are not aspirations but realities for every person with albinism.

Djaffar Moussa-Elkadhum

Chair of the Board

# **List of Acronyms**

AAN Africa Albinism Network

ACERWC African Committee of Experts on Rights and Welfare of the Child

**ACHPR** African Commission on Human and Peoples' Rights

AU African Union

**CEDAW** Committee on the Elimination of All Forms of Discrimination Against Women

**CESCR** Committee on Economic, Social, and Cultural Rights

CRC Committee on the Rights of the Child

**CRPD** Committee on the Rights of Persons with Disabilities

**EML** Essential Medicine's List

HRC Human Rights Council

**HRDs** Human Rights Defenders

IAAD International Albinism Awareness Day

NAP National Action Plan

**OHCHR** Office of the United Nations High Commissioner for Human Rights

PAP Pan African Parliament

**UN** United Nations

WADR West Africa Democracy Radio

WHO World Health Organization

WiA Women impacted by Albinism

WLF Women's Learning Forum



# **Africa Albinism Network**

The Africa Albinism Network (AAN) has deep expertise in addressing the issues affecting people with albinism. AAN was founded in February 2021 by the inaugural UN Independent Expert on the rights of persons with albinism, Ms. Ikponwosa Ero, after laying almost two decades of groundwork that has seen successful engagements and policy commitments globally to protect people with albinism.

#### Vision Mission

Toward an Inclusive World, Free from Brutality and Discrimination

#### Thematic Areas Values

- · Human Rights Defenders
- · Women Impacted by Albinism
- · Climate Change and Albinism

A Culture of Accountability & Integrity

capacity development, and collaboration.

Center the Voices of People with Albinism

To promote the rights, well-being, and inclusion of

people with albinism in Africa through advocacy,

- Prioritize Collaboration and Partnerships
- · Equity and Inclusion
- Justice & Human Rights

#### **Approach**

- Human Rights-Based Approach (HRBA):
   This transformative approach empowers individuals with albinism as rights-holders, demanding accountability from states and institutions as duty-bearers.
- Capacity Development: To ensure the sustainability of our movement and its successes, AAN supports the capacity development of human rights defenders (HRDs) and partners in our work.
- Collaborations & Partnerships: Collaboration and partnerships are vital to addressing the complex and wide-ranging issues facing people with albinism in Africa, from the egregious human rights violations to the impacts of climate change, gender-based violence, and health disparities.
- Research & Data: We believe that data is indispensable to our vision of an inclusive world, free from brutality and discrimination.



# **Africa Albinism Network**

#### **Team**

#### Staff

- Ikponwosa "I.K." Ero
- Martin Haule
- · Annabahati Gwacha
- · Haingo Rakotomalala
- · Kwame Andrews Daklo
- Doreen Mkatomboka
- Lubabatu Abubakar
- Mary Asuquo (Intern)

#### **Governing Board**

- Djaffar Moussa-Elkadhum (Chair of the Board)
- Thando Hope (Vice Chair of the Board)
- Innocentia Mgijima-Konopi
- Mawunyo Yakor-Dagbah

#### **Senior Advisers**

- Alison Hillman
- Christine Lancing
- Pearl Gottshalk

#### **Language Liaisons**

- Frank Hounsa (French)
- Joaquina Rodriguez (Portuguese)



# Tanzania adopts a National Action Plan

To commemorate the International Day of Persons with Disabilities on December 3rd, 2024, the Government of Tanzania officially adopted a National Action on Albinism titled "National Action Plan of Rights and Welfare of Persons with Albinism" in Dar es Salaam, Tanzania. Hon. Dr. Doto Mashaka Biteko, the Deputy Prime Minister, presided over the launch as the guest of honor.

# Joint Human Rights Advocacy with Albinism Groups

In 2024, AAN collaborated with 20 albinism groups to submit 13 joint reports to shape discourse and implement the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021-2031) at ACERWC, ACHPR, CEDAW, CESCR, CRPD, HRC, and OHCHR.

#### Campaign for the protection of Persons with albinism against skin cancer

2024 marked the 10th anniversary of June 13<sup>th</sup> - International Albinism Awareness Day (IAAD). To commemorate the decade, AAN launched a petition urging the World Health Organization (WHO) to re-add sunscreen to the list of essential medicines. 4282 signatures were gathered across 99 countries.

# First Regional Learning Forum for Women with Albinism

In May 2024, AAN organized the first Regional Learning Forum for women human rights defenders with albinism. 28 women from 17 African countries gathered in Nairobi for an immersive and holistic three-day forum to network, learn, share, and exchange their experiences with such passion and determination.



- A strengthened and more impactful albinism movement across Africa.
- The representation of women with albinism in leadership positions across Africa triples because of AAN's mentoring program. Accompanying peer support networks are successful in promoting a sense of solidarity and resilience, reducing self-stigma, contributing to individual and collective well-being, and empowering women with albinism to advocate for their representation and their rights.
- The quality, effectiveness, and impact of decisions made within policy frameworks on issues impacting persons with albinism are vastly improved, including broader and more inclusive consultation processes reflecting the active involvement of persons with albinism.

- Raise awareness among stakeholders of the importance of additional measures for skin cancer treatment and prevention by conducting advocacy to include sunscreens on the World Health Organization's Essential Medicine's List.
- Robust cross-movement
   collaborations exist with
   organizations working in the
   thematic areas of climate
   change, women's rights, and
   human rights defenders to ensure
   that the voices and issues of
   persons with albinism are included
   in these spaces and to contribute
   toward building stronger, more
   resilient, and inclusive rights
   movements.



The UN Independent Expert on Albinism emphasizes that albinism group leaders must be recognized as human rights defenders (HRDs) for effective protection. Without this recognition, they lack awareness of their rights, support networks, and state protection. In 2024, AAN submitted 13 joint reports with albinism groups to shape discourse and implement the AU Plan of Action on Albinism at AU and UN human rights mechanisms.

### Capacity Development of HRDs with Albinism

- Baidon Chandipo (Albinism Foundation of Zambia) physically delivered a statement at the 55th Session of the HRC in Geneva.
- Chikondi Kandjaza (Standing Voice Malawi) presented a virtual statement at the 56th Regular Session of the Human Rights Council (HRC).
- Nontsikelelo Loteni (South Africa Albinism Task Force) delivered a presentation on the rights of children with albinism for a seminar titled "Agenda 2063 Fostering an Africa Fit for Children" at the Pan African Parliament in South Africa.

## **Empowering the leaders of tomorrow at the African Union**

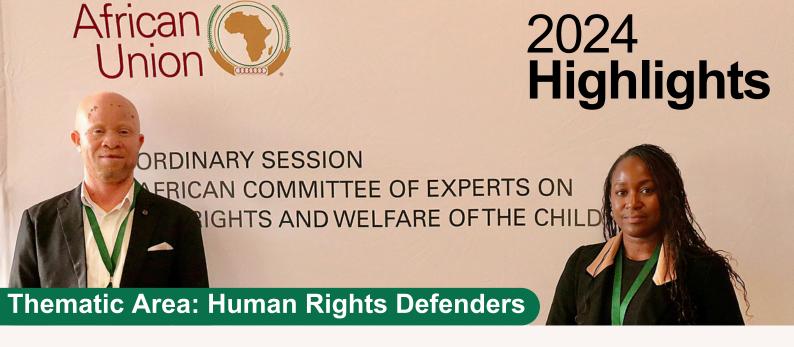
AAN supported the participation of four youths with albinism from Tanzania who were survivors of various human rights violations to present statements at the 43rd Ordinary Session of the African Committee of Experts on the Rights and Welfare of the Child (ACERWC) of the African Union in Lesotho. They shared their lived experiences and provided recommendations on the challenges they face.



We believe it's the responsibility of our governments to take care of our health. We need them to provide sunscreen for free and train more dermatologists and low vision specialists.

Statement by Mwigulu Matonange on the rights to health for children with albinism in Africa



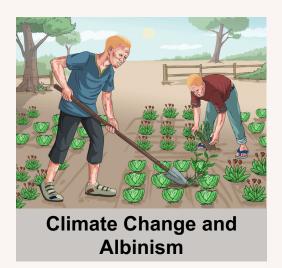


#### **Resourcing Human Rights Defenders with Albinism and Allies**

In 2024, the Human Rights Advocacy team developed **three mini Human Rights Advocacy toolkits for human rights defenders with albinism and allies** on climate change and women's and children's rights.



Empowering Women with Albinism: A Checklist for Advocacy Success!



Mini Advocacy toolkit on Climate Change and Persons with Albinism



Women and Children with Albinism

Mini Advocacy Toolkit for Women Impacted by Albinism and Children with Albinism



AAN supports women impacted by albinism, both women with albinism and mothers of children with albinism, to contribute to positive outcomes in the Africa region and to strengthen their presence in leadership in the albinism movement to ensure better representation, as women account for about half of the movement's beneficiaries. In 2024, AAN focused on developing the leadership skills of women with albinism and spotlighting leaders in the movement through capacity development and storytelling.

AAN's 2022 pan
African survey across
48 African nations
found that only 30%
of movement leaders
are women with
albinism.

# International Women's Day 2024

For International Women's Day 2024, we celebrated two women leaders with albinism who have achieved great success in their communities by interviewing them on their journeys to leadership.



Mawunyo Yakor-Dagbah Ghana

Read the Blog



**Maimouna Dene** *Burkina Faso* 

Read the Blog



#### Breaking new ground: AAN Women's Learning Forum 2024

From May 28th to 30th, 2024, 28 women impacted by albinism from 17 African countries and albinism groups convened in Nairobi, Kenya, for the Africa Albinism Network's (AAN) **inaugural Women's Learning Forum.** 

The objective of the forum was to address some of the most pressing issues faced by women and children impacted by albinism. Traditionally, men have occupied leadership positions within the albinism community and civil society, leaving little space for the development of women's voices and leadership. A recent survey by the AAN in 2022 and 2023 indicated that only 30 percent of albinism leaders are women, and only 16 percent of albinism groups prioritize the issues of women impacted by albinism.

The Swahili saying "Umoja ni nguvu," which means "Unity is strength," perfectly encapsulates the spirit of the Forum because never in the history of Africa have so many women impacted by albinism gathered in one space to network, learn, and share their experiences with such passion and determination.



The Forum improved my leadership skills and networking and also my personal growth in terms of business; hence, I was able to train other people with albinism in business and also in self-defense.

**AAN WLF 2024 Participant** 





**United Nations**Climate Change



**COP29** Baku Azerbaijan



#### Thematic Area: Climate Change and Albinism

Climate change poses an existential threat to persons with albinism. Deforestation exacerbates their vulnerability to the sun's rays, as they often work outdoors due to educational barriers and bullying. AAN addresses this by equipping albinism organizations with advocacy skills to engage the AU and UN to integrate their concerns into climate change discourse. In 2024, AAN invested in building partnerships with CBM Global to support the inclusion of persons with albinism in climate change discourses globally.

#### The Push for a More Inclusive Climate Movement at COP29

Our Advocacy Manager joined hundreds of activists and decision-makers at COP29 in Baku to discuss the planet's most pressing environmental challenges and to promote the petition urging the WHO to add sunscreen to the Essential Medicines List.

**Read the Blog** 







#### Campaign: Petition to Protect People with Albinism from Skin Cancer

To mark the 10th anniversary of International Albinism Awareness Day (IAAD) 2024, we launched a petition urging the World Health Organization (WHO) to re-add sunscreen to the list of essential medicines. The petition letter was signed by 4,282 people in 99 countries across 6 WHO regions.

Click to read the full Petition Impact Report



**75** 

Albinism organizations worldwide signed the petition.

10,282

We developed campaign resources to support the petition. They were viewed 10,282 times on social media.

95,279

Our campaign message reached 95,279 people across Facebook, Instagram, X, LinkedIn, and YouTube.



CBM Global is deeply committed to this important climate justice campaign led by the Africa Albinism Network.

For people with albinism, sunscreen is truly a life-saving medical product."

**David Bainbridge, Executive Director of CBM Global** 





In 2024, AAN partnered with development partners, academic institutions, civil society, and the media to raise awareness and promote the AU Plan of Action on Albinism to address the complex and wide-ranging issues affecting persons with albinism in Africa, such as access to justice, the impact of climate change, and health disparities.

#### Implementing the AU PoA: Tanzania adopts a NAP!

In February 2024, AAN supported a Stakeholder's Engagement workshop with development partners and civil society in Tanzania led by the UN Independent Expert on Albinism focusing on people with albinism. On December 3<sup>rd</sup>, 2024, to commemorate the International Day of Persons with Disabilities, **the Government of Tanzania adopted a NAP** titled "National Action Plan of Rights and Welfare of Persons with Albinism."



We need to ensure that the government does not see this as just a document but as a commitment to protecting our community. We cannot do this alone; we need continuous collaboration.

Salehe Alex, Program Manager at the Tanzania Albinism Society



#### Launch: "Out of the Shadows for Good" Project in Zambia

In October 2024, AAN launched the "Out of the Shadows for Good" project in partnership with Liliane Fonds and Cheshire Homes Society of Zambia. The project spans three years and works closely with albinism groups in Zambia to protect the rights of persons with albinism, combat stigma, and provide access to critical resources like justice, healthcare, and education.



#### **Raising Awareness through Media Engagement**

We partnered with the West Africa
Democracy Radio (WADR) to produce
and air a two-part radio program on
climate change and albinism in
English and French as part of their
weekly program titled "Enviroscope,"
which brings to the fore topical issues
affecting the agriculture sector, land
exploration, and climate change.





To commemorate the 10th anniversary of International Albinism Awareness Day (IAAD), AAN's Advocacy Manager, Kwame Andrews Daklo, joined other prominent albinism leaders from Nigeria at a thought-provoking webinar hosted by Prime Progress, a media outlet documenting how people are responding to social problems in Nigeria.



#### **Partnering with Academia for Inclusive Advocacy**

University of the Free State roundtable on healthcare and education for persons with albinism

Our Advocacy Manager, Andrews Kwame Daklo, gave a virtual presentation on climate change's impact on health and called for sunscreen to be reinstated on the WHO Essential Medicines List. The session raised awareness, encouraged dialogue, and mobilized support for improving the well-being of persons with albinism across Africa.



# Center for Human Rights - University of Pretoria's Advanced Human Rights Course on Disability Rights in an African Context

AAN's Advocacy Manager, Kwame Andrews Daklo, gave a presentation titled "Addressing Human Rights Violations Against Persons with Albinism in Africa: How Far Have We Come?" He emphasized that addressing the human rights violations of people with albinism in Africa requires a multifaceted approach that combines legal reforms, educational initiatives, and community engagement.

# 2025: Year ahead

#### Leadership transition at AAN: Celebrating I.K. Ero, Welcoming Bonface Massah

In 2024, after almost 4 years of transformative leadership, we bid farewell to Ikponwosa "I.K." Ero as Executive Director of the Africa Albinism Network (AAN) and welcome Bonface Massah as Executive Director.

I.K.'s vision and dedication have elevated AAN's mission at the continental level, and we are thrilled she'll remain with us as a Senior Adviser. Bonface brings over 15 years of advocacy experience, championing the rights of persons with disabilities, including those with albinism, across Africa. His passion and expertise promise an inspiring new chapter for AAN.



#### **A New Strategic Direction**

AAN is at a crossroads in its evolution, ready to move from the founder's stage of an entrepreneurial startup that successfully validated its proof of concept with several successful projects. In this second stage of growth and scaling, AAN aims for a cohesive, strategic, and focused path forward, steeped in learning from its history. The goal is strategic growth in impact coupled with organizational strength and sustainability.

In 2024, AAN began a reflection on its new strategic vision and embarked on a strength-based strategic planning process. Through listening to its diverse stakeholders, AAN conducted a situational analysis and gained clarity on identity and direction.

The plan articulates AAN's Strategic Framework and Theory of Change, aligning all parts of the organization towards its targets. To bring focus to our collective priorities, six strategic pillars lay the foundation for the strategic plan. They are:

- Human Rights-Based Advocacy
- Capacity Development for and of Albinism groups and Human Rights Defenders
- Collaboration and Partnership
- Become a Resource Hub for Research, Data, and Dissemination
- Sustained Organizational Growth



We are grateful for the generous financial contributions of our funding partners and our partnerships with various organizations and human rights defenders with albinism who have supported our work in 2024.

#### **Funding Partners**

- Ford Foundation
- Global Greengrants Fund

#### **Partner Organizations**

- Adonai Studios
- CBM Global Disability Inclusion
- Center for Human Rights University of Pretoria
- Cheshire Homes Society of Zambia
- Climate Action Network (CAN)
- Empower Limited
- Human Rights Watch
- International Commission of Jurists (ICJ)
- KanariMaqik
- Lumen East Africa

- Liliane Fonds
- Under the Same Sun (UTSS)
- O'Neill Institute for National and Global Health Law
- · Prime Progress Nigeria
- Smile Child Organization
- Tamarind Language Services
- UNESCO Namibia
- University of Free State South Africa
- UN Women East and Southern Africa Regional Office
- Vrije Universiteit Amsterdam
- West Africa Democracy Radio (WADR)

#### **Human Rights Defenders with Albinism**

- Adam Abdul Wahab
- Baidon Chandipo
- Chikondi Kanjadza
- Diandra Forrest
- Isaac Mwaura
- Jane Waithera
- Joselito Pereira da Luz

- Maimouna Dene
- Nomasonto Mazibuko
- Nontsikilelo Loteni
- Nnene Bassey
- Peter Ogik
- Simon Kalenga
- Xueli Abbing



We also extend our gratitude to the albinism organizations, the UN mandate, and individual collaborators who have supported our work in 2024.

#### **Albinism Organizations & Mandate**

- · Albinism Multipurpose Organisation
- Albinism Foundation of Zambia (AFZ)
- · Albinism Royal Foundation
- Albino-Multipurpose Association of Lesotho
- Association Nationale des Albinos du Togo (ANAT)
- Association of Persons with Albinism in Malawi (APAM)
- Black Albinism
- Divine Connexion Worldwide (DCW)
- Fundação Joel Tchombosi
- Ghana Association of Persons with Albinism (GAPA)
- Global Albinism Alliance (GAA)
- Mandate of the UN Independent Expert on Albinism
- Mothering & Albinism
- Namibia Association for Persons with Albinism (NAPA)

- National Albinism Taskforce of South Africa (NATF)
- National Organization for Albinism and Hypopigmentation (NOAH)
- ONG Valeurs Albinos
- Positive Exposure Kenya
- Sierra Leone Association of Persons with Albinism (SLAPWA)
- Sierra Leone Albinism Foundation (SLAFo)
- Support in Namibia for Albinism Sufferers Requiring Assistance (SINASRA)
- SOS Albinos Mali
- Standing Voice
- Tanzania Albinism Society (TAS)
- Upendo Wa Mama
- Village of Hope

#### Individual collaborators

- Bohang Benedix
- Bruce Chooma
- Diane Bourne
- Elisabeth Martin
- Lefhoko Kesamang
- Lizzie Kiama

- Maadia Thiam
- Margaret Waruiru
- Masoud Kipanya
- Michael Gyan Nyarko
- Peter Fremlin
- Thomas Ero

# **Financials**

#### **EXPENSES (\$ US)**

**Theme:** Human Rights Defenders

Theme: Women impacted by Albinism Theme: Climate Change and Albinism

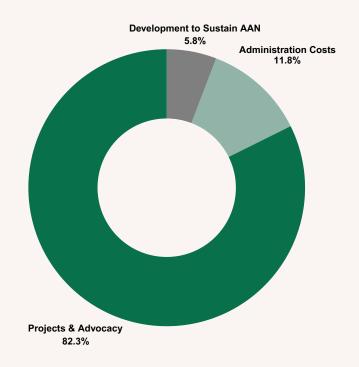
**Administration Costs** 

Development to Sustain AAN

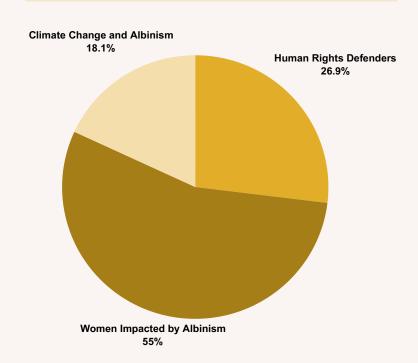
#### **Total Expenditure**

2024
94,530
192,887
63,676
50,306
25,020
426.419

#### **Breakdown of Expenses**



#### **Breakdown by Thematic Areas**



# **Photo Captions**

- Cover page: Participants at the Women's Learning Forum 2024. Nairobi, Kenya. May 2024
- Page 1: Photo of AAN Chair of the Board
- Page 3: Official group photo of participants. Women's Learning Forum 2024. Nairobi, Kenya.
   May 2024
- Page 4: The AAN Team wearing their respective cultural attire at the Women's Learning Forum 2024. Nairobi, Kenya. May 2024
- Page 5: Shot on the set of the short film commissioned by AAN in Ghana titled "Climate of Concern" on Climate change and Albinism.
- Page 6: Participants at the Women's Learning Forum 2024 during a session on Empowerment Self-Defense. Nairobi, Kenya. May 2024
- Page 7: Child representative from Tanzania speaking at the 43<sup>rd</sup> Ordinary session of the ACERWC. Maseru, Lesotho. April 2024
- Page 8:
  - Main photo: Two AAN Staff at the 43<sup>rd</sup> Ordinary session of the ACERWC. Maseru, Lesotho. April 2024
  - Smaller photo: Child with albinism praying © UTSS
- Page 9: 3 Participants at the Women's Learning Forum 2024. Nairobi, Kenya. June 2024
- Page 10: Group mentorship session at the Women's Learning Forum in Kenya. Nairobi, Kenya.
   May 2024
- Page 11:
  - Main photo: AAN Advocacy Manager at COP29. Baku, Azerbaijan. November 2024
  - Two smaller photos: Petition signatories at COP29. Baku, Azerbaijan. November 2024
- Page 12: Illustration commissioned by AAN of Joselito Pereira da Luz, a Brazilian human rights defender with albinism for the campaign petitioning the W.H.O to re-add sunscreen to the EML.
- Page 13: Launch of the Out of the Shadows for Good Project. Lusaka, Zambia. October 2024
- Page 14: AAN with partners at CBM Global Disability Inclusion at COP29. Baku, Azerbaijan.
   November 2024
- Page 15:
  - Main photo: AAN staff with Village of Hope and UTSS at NOAH Con 2024. Orange County
     California, USA. July 2024
  - Small photo: Group photo at the University of Free State South Africa Roundtable.
     November 2024 © UFS
- Page 16: Portrait photo of Bonface Massah
- Page 17: Stakeholder's Engagement. Dar es Salaam, Tanzania. January 2024
- Page 18: (L-R) Lefhoko Kesamang and Nomasonto Mazibuko at the Women's Learning Forum 2024 celebrating their honorary awards from AAN for advocating for the rights and well-being of people with albinism. Nairobi, Kenya. May 2024

# Thank you and we look forward to your continued support.

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