



INVITATION

The Faculty of Law's Disability Rights Unit, the Dermatology Department (Faculty of Health Sciences), and the Unit for Institutional Change and Social Justice invites you to a Round Table Discussion on access to healthcare and education for persons with albinism, as part of the Disability Rights Awareness Campaign.

ROUNDTABLE DISCUSSION ON ACCESS TO HEALTHCARE AND EDUCATION FOR PERSONS WITH ALBINISM

Date: 12 November 2024

Venue: Hybrid (Face-to-Face: School of Financial Planning Law, University of the Free State, Bloemfontein Campus)

Organised by: Faculty of Law- Disability Rights Unit and Faculty of Health Sciences- Dermatology department

Background

Access to healthcare and education for persons with albinism are critical issues that impact their quality of life and well-being. Skin cancer risk, vision impairment, and discrimination are realities which need specialised medical care and support. The specialised healthcare services tailored to their specific needs, such as eye care, skin cancer prevention or psychosocial support, are often unavailable or very limited. Furthermore, discrimination, stigma, and the lack of knowledge about albinism create additional hindrances to seeking and accessing necessary healthcare services. Consequently, several persons with albinism are unable to enjoy their fundamental human right to healthcare. Considering the advancements in health, measures to improve the availability, accessibility and quality of healthcare services for persons with albinism are necessary. In the same vein, education systems also need to approach albinism in a manner that addresses discrimination, stigmatisation, lack of reasonable accommodation, and inadequate support for learning. Many learners with albinism and their families face difficulties accessing education and even drop out.

In light of these realities, this one-day roundtable event seeks to bring together different experts to discuss access to healthcare and education by persons with albinism and ways to protect their healthcare and education rights. The focus contributes to reflections on the continued legal, policy and practical changes still needed to ensure the full and equal enjoyment of rights by persons with albinism. The date falls within disability rights awareness month.

Objectives

The expert roundtable will seek to:

- Discuss challenges that persons with albinism experience accessing healthcare and education and possible solutions to these.
- Facilitate opportunities for future cooperation between departments and organisations working on matters affecting persons with albinism.

Structure

The roundtable will take place over one day. Each session will begin with short presentations by experts working on albinism-related matters, and then it will proceed to a Q&A session. The sessions will focus on four areas i) access to healthcare and specialised medical care, ii) education and inclusion, iii) psychosocial support and combating stigma, and iv) protecting the health and education rights of persons with albinism.

The roundtable discussion will also include exhibitions by artists who are living with albinism. These artists will be presenting their work either in person or on the virtual platform.

Outputs

The roundtable discussion will result in papers that will be compiled into a consolidated publication.

The discussion will also ensure the groundwork for an International Conference on the Rights of Persons with Albinism to be held in 2025. The specific topics and date of the conference will be established following the discussion.

Participants

The event will have a hybrid format and have a maximum of 50 in-person participants. These participants will include scholars, members of civil society and policymakers.

Proposed Sessions in Summary

Opening session

Triumphs and challenges of persons with albinism in South Africa 30 years after democracy

Commissioner Nomasonto Mazibuko, Albinism Society of South Africa

Session 1: Access to health care and specialised medical care
(Health challenges and complications faced by persons with albinism; Barriers to accessing suitable and quality healthcare; **Enhancing the accessibility and availability of specialised healthcare services (ophthalmology, dermatology)**)

Session 2: Education and inclusion
(Ensuring reasonable accommodations and support; Promoting awareness and understanding amongst educators)

Session 3: Psychosocial support and combating stigma
(Psychosocial challenges faced by persons with albinism; ways to enhance psychosocial support and deal with myths and misconceptions about albinism)

Session 4: Protecting the rights of persons with albinism
(How the rights of persons with albinism can be protected and fulfilled in accordance with international human rights standards)

Exhibition: Representation by artist living with albinism

www.ufs.ac.za

Inspiring excellence, transforming lives through quality, impact, and care.



HEALTH SCIENCES
UFS



VISION 130
Renew and Reimagine
towards 2034

UNIVERSITY OF THE
FREE STATE
UNIVERSITEIT VAN DIE
VRYSTAAT
YUNIVESITHI YA
FREISTATA

