

MOTHERING AND ALBINISM 2025



NEWSLETTER

As we approach the holiday season, we want to extend our warmest wishes to each of you. Thank you for your dedication, hard work, and partnership in advancing our shared mission to support the rights and well-being of persons with albinism around the world.



WHO RESTORED SUNSCREEN IN THE MODEL LIST OF ESSENTIAL MEDICINES

We congratulate Muluka-Anne Miti-Drummond and those involved whose leadership and advocacy led to the re-addition of sunscreen in the World Health Organization's Model List of Essential Medicines in September 2025. This decision will support our collaborative efforts to combat the detrimental impact of skin cancer affecting many persons with albinism.

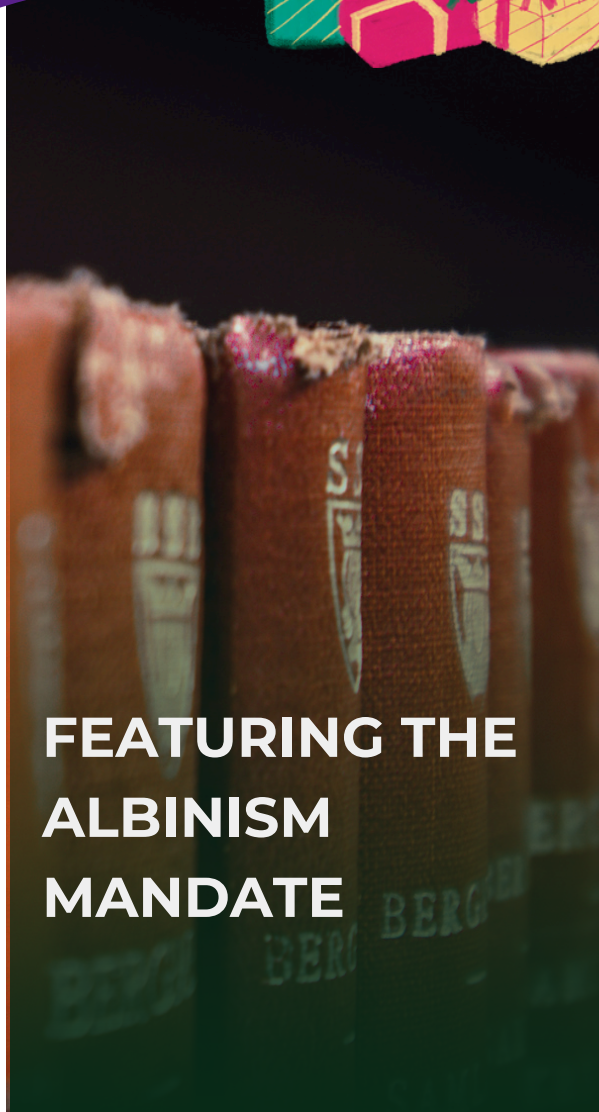
You can read the full WHO report [here](#).

GUIDING NOTE ON REPORTING ON THE RIGHTS AND WELFARE OF CHILDREN WITH ALBINISM IN AFRICA

We also highlight this year's release of the guiding note on reporting on the rights and welfare of children with albinism in Africa. According to Miti-Drummond, "this tool supports African Union Member States to better report, protect, and promote the rights of children with albinism—addressing discrimination, violence, exclusion, and barriers to education, healthcare, and justice."

Read the Guiding Note [here](#).

FEATURING THE ALBINISM MANDATE



PROJECT UPDATES

PHASE I: PARTICIPATORY SYSTEMATIC REVIEW AND OTHER PAPERS

Our team has been progressive throughout the year in disseminating our research findings. Our students published papers on albinism:

- Led by Kiel Mayich - [The Situation of Mothers Impacted by Albinism in sub-Saharan Africa: A Video Analysis](#)
- Led by Meghann Buyco - [Access to Healthcare by Mothers Impacted by Albinism in South Africa](#)

Recently, our participatory systematic review has been published. All of you contributed to this paper, remembering our consultation in Pretoria

- Co-led by Sheryl Reimer-Kirkham and Kendra Rieger - [A Participatory Systematic Review on Human Rights and the Birth of a Child with Albinism in sub-Saharan Africa](#)



The following article is currently in press:

- Led by Sheryl Reimer-Kirkham - A Comparative Analysis of the Critical Resilience and Gender Equity of Mothers Impacted by Albinism: Promising Practices from Tanzania and South Africa

We will continue our efforts to broaden understanding, challenge misinformation, and amplify the voices and lived experiences of persons with albinism and their families. Our intersectoral, interdisciplinary team is allowing us to publish for a wide-ranging audience. See our full list [here](#).



PHASE II: DATA COLLECTION AND ANALYSIS UPDATES

We are pleased to share that data collection for our project is now complete in Canada and South Africa and nearly finished in Ghana. We have gathered data from a total of 160 participants. Our South Africa team—led by Shirley Mooa with coordination by Innocentia Mgijima-Konopi—has been outstanding, with special appreciation for the dedication of Ronell Leech, Victoria Nesengani, Mpho Tjope, and Nomasonto Mazibuko, our community researchers (Sizo Gabela, Rina Hlelo Mehlomakulu-Mato, Khululwa Shibani, Makhanthisa Thomas), as well as student contributors (Tumisho Mokwele and Thulisile Mahlangu) and





the 2024 student interns (Samkelo Mindebele and Definitely Mutsvangwa).

In Ghana, data collection has been led by Lillian Ohene, with valuable contributions from her student, Adwoa Agyare, team member, Kwame Daklo, and 2024 student intern, Suhuyini Seidu.

With these milestones achieved, our team is now moving into the data analysis phase and progressing with coding using NVivo.

- Policy Brief on RMC, Disabilities, and Albinism (led by IK Ero and Barb Astle).
- Clinical Practice Guideline (led by Sheryl Reimer-Kirkham and team)
- Human Rights Education in the Health Professions (led by Sheryl Reimer-Kirkham and Shirley Mooa).

Barb Astle is leading the development of a Toolkit for Health Educators that will incorporate the work of the Collaborative Action Groups.

MEET THE INTERNS

In September 2025, six new undergraduate students joined our internship program, representing our four country sites: South Africa, Tanzania, Ghana, and Canada. They will engage in Phase III of our Action Cycles for knowledge dissemination of our findings and supporting other advocacy efforts. We are excited to introduce:

- Tunu Kibe, Trinity Western University
- Kizito Koinet Kileu, Aga Khan University
- Nsindiso Masiya, University of Pretoria
- Anitha Francis Mganga, Aga Khan University
- Malesolo Yvonne Mogano, University of Pretoria
- Lisa Fanuel Ompeshi, Aga Khan University

You can read more about them in their introductory blog [here](#).



PHASE III: ACTION CYCLES

We will begin the Phase III Collaborative Action Groups in January 2026. In the next weeks, you will receive an email inviting you to join one of the groups, which will meet four times from January to May. These action groups will work collaboratively to create knowledge translation materials:

- Digital Stories (led by Mike Lang and Kendra Rieger). The digital storytelling workshop will be held in South Africa in March.



INTERNATIONAL ALBINISM CONFERENCE, LANCASTER

In September 2025, some of our Mothering and Albinism team presented at the International Albinism Conference hosted at Lancaster University by the School of Global Affairs. To mark 10 years of the mandate of the Independent Expert on the Rights of Persons with Albinism, the conference brought together albinism advocates, associations, and human rights defenders, and researchers from a range of disciplines and those working across disciplines.

We presented a Roundtable titled “Strengthening Human Rights Advocacy Approaches Along the Lines of Gender, Disability, and Albinism”:

- Chaired by Elvis Imafidon (SOAS, University of London)
- Sonya Sharma (University College London) addressed the theoretical foundations considerations for the study of gender and albinism
- Barbara Astle (Trinity Western University) described the intersectoral approaches to research on albinism and human rights
- Ikponwosa Ero (Africa Albinism Network) presented recommendations countering sexual and gender-based violence and empowering women with disabilities, including women impacted by albinism
- Kendra Rieger (Trinity Western University) analyzed how to mitigate the experiences around the birth of an infant with albinism that are imbricated with violence
- Sheryl Reimer-Kirkham (Trinity Western University) explored how human rights defenders—women impacted by albinism themselves and community and faith leaders—become more impactful through agency and capacity-building

You can read more [here](#).



DR. SHIRLEY MOOA, VISITING SCHOLAR

 TRINITY WESTERN UNIVERSITY

Graduate Seminar | November 24, 2025
4:30-6:30 p.m. (PST)

**(Re) learning the Past Matters in Nursing Education:
University of Pretoria, South African Case study**

This presentation will focus on the *small steps* that can be incorporated in introducing other ways of knowing, (including traditional knowledges), healing, and health in the Eurocentric nursing curriculum. These steps may strengthen the culturally responsive and integrative approaches to care for nursing students' working in diverse practice environments.

Join us in-person in the Fosmark Boardroom and Online ([Zoom](#))



Professor Ramadimetja (Shirley) Mooa, PhD (University of Alberta)

Shirley is a visiting scholar at the TWU School of Nursing and is the head of the nursing department at the University of Pretoria, South Africa. Her area of specialization and interests are African-centred methodologies, Qualitative (Ethnography), Quantitative, Mixed methods; Multi-inter-trans-disciplinary and inter-professional (MITI) Methodology). Research interests include Women's health, Violence against women, African Knowledge

Graduate Seminar Overview

4:30 PM Welcome and introduction
4:45 PM Presentation
5:30 PM Discussion
6:30 PM Closing

Hosts:

Dr. Barbara Astle, RN, PhD, FCAN, FAAN
Associate Dean, MSN Program and Professor,
School of Nursing

Dr. Sheryl Reimer-Kirkham, RN, PhD, FCAN, FAAN
Dean and Professor,
School of Nursing

Dr. Shirley Mooa, from the University of Pretoria, recently joined us at Trinity Western University as a Visiting Scholar. We are deeply grateful for her time, expertise, and warm presence during her visit. Shirley worked on two manuscripts drawing on South African data, and presented an inspiring seminar entitled “(Re)learning the Past Matters in Nursing Education: University of Pretoria, South African Case.” Shirley, Barb, IK, and Sheryl met in Edmonton for a two-day intensive writing and planning retreat that was focused on bringing the project from Phase II into Phase III.



“Wishing you a wonderful holiday season and all the best for the year ahead.”

Sheryl, Shirley, Barb, & IK





Project Team



Sheryl Reimer-Kirkham (CA), Ramadimetja Shirley Mooa (SA); Barbara Astle (CA); Ikponwosa Ero (CA/NG); Mary Ani-Amponsah (GH); Lydia Aziato (GH); Lori Beaman (CA); Kwame Andrews Daklo (GH); Maretha de Waal (SA); Duncan Dixon (CA); Bonny Ibhawoh (CA); Elvis Imafidon (NG/UK); Jennifer Kromberg (SA); Michael Lang (CA); Ronell Leech (SA); Nomasonto Mazibuko (SA); Innocentia Mgijima-Konopi (SA); Muluka-Anne Miti-Drummond (ZM); Dianah Msipa (SA); Tintswalo Victoria Nesengani (SA); Lillian Ohene (GH); Kendra Rieger (CA); Perpetua Senkoro (TZ); Sonya Sharma (UK); Eunice Siaity-Pallangyo (TZ); Landa Terblanche (CA); Wisdom Tettey (CA); Mpho Tjope (SA); Boateng Wiafe (GH); Meghann Buyco (CA); Karen Larochelle (CA); Tumisho Mokwele (SA); Emma Strobell (CA); Ingrid Watts (CA)



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