

2026 NEWSLETTER

WWW.MOTHERINGANDALBINISM.COM



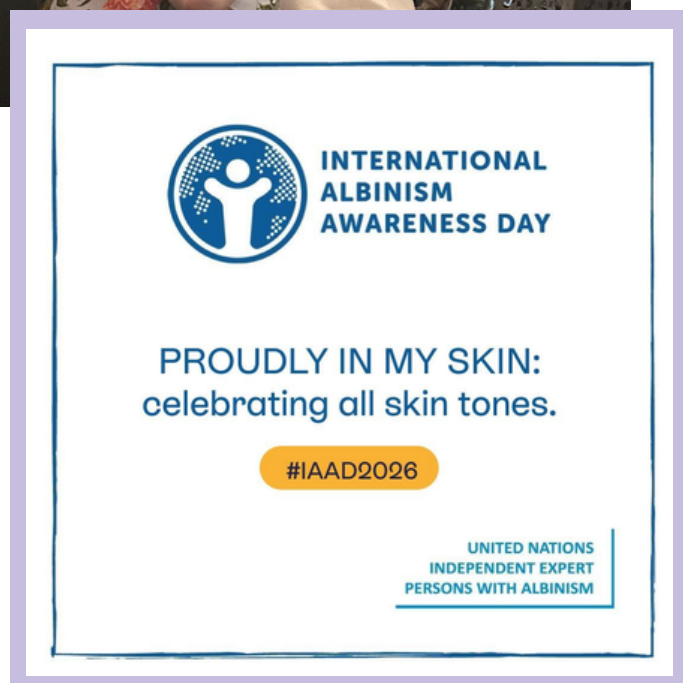
June 2026



International Albinism Awareness Day

This June 13th, 2026, we celebrated the annual International Albinism Awareness Day, which was grounded in the theme: "Proudly in my Skin: Celebrating All Skin Tones". It aims to combat skin-based discrimination, centre the voices of persons with albinism, and promote equal, safe, and inclusive environments. As an international research-advocacy-policy network, we are committed to the full enjoyment of human rights by persons with albinism worldwide.

Please see Malesolo Yvonne Mogano's (student intern) blog, honouring the International Albinism Awareness Day with a reflexive blog with Tshego Keitsemore's digital story. [Click here](#).



Phase II Updates

The data from 162 interviews and focus groups have been coded in NVivo™ (qualitative software). We have created a shared codebook for the 3 data sets (South Africa, Canada, and Ghana), but are keeping the projects separate for now while we complete country-specific analyses, weaving and drawing out the storylines. With this early step in analysis complete, we are now conducting thematic analysis, following the method of Interpretive Description ([Thorne, 2025](#)) to write country-specific papers. The Canadian manuscript is well underway but has been paused during Phase III Collaborative Action Group initiatives. The South African team is meeting in July for a week-long writing retreat to outline and write a few key papers. The Ghana team has begun meeting weekly to outline their first overview paper. Little has been written about human rights and the psychosocial aspects of albinism in both Ghana and Canada, so these will be important contributions to the field. As the country-specific papers are being written, we are sketching out thematic papers that draw on the entire data set (including the earlier SSHRC data from Tanzania).



Phase III Updates

Since January, we have been actively engaged in Phase III of our research project, developing four key knowledge translation outputs:



- **Digital Stories** (led by Kendra Rieger, Michael Lang, Ramadimetja Shirley Mooa, Innocentia Mgijima-Konopi and Mpho Tjope, with interns Nsindiso Masiya, Malesolo Yvonne Mogano, and Lisa Fanuel Ompeshi)
 - A Digital Storytelling Workshop was held in Pretoria, South Africa, in March 1-6 2026, bringing together parents of children with albinism, healthcare providers and educators, and advocates who generously shared their experiences and created eight digital stories illuminating their lived experiences in compelling ways.
 - Next steps include finalizing the stories, adding subtitles, translating them into one local language for each of our four country sites, and developing facilitation guides to support their use in education and community engagement.
- **Care Pathway Clinical Practice Guidelines** (led by Sheryl Reimer-Kirkham, with interns Kizito Koinet Kileu and Anitha Francis Mganga)
 - Through consultation meetings and evidence-informed data extraction conducted by our interns, we developed a series of Good Practice Statements to guide healthcare providers in supporting mothers who have given birth to a baby with albinism, from birth through early childhood.
 - The next phase involves validating the Care Pathway with healthcare providers across our study sites.
- **Policy Brief** (led by Barb Astle and IK Ero, with intern Tunu Kibe)
 - We facilitated consultation meetings to develop a policy brief focusing on advancing disability inclusion within Respectful Maternity Care.
 - The brief is currently being adapted for different target audiences, including policymakers, academics, and the general public.
- **Human Rights Framework** (led by Sheryl Reimer-Kirkham, IK Ero, Shirley Mooa, and Ronell Leech, with master's student Christa Wilton)
 - Through a series of dialogues and consultations, along with an annotated bibliography by Christa, we developed a human rights framework designed as a practical educational resource for health professions educators.
 - The framework is currently being refined and will be developed into a peer-reviewed manuscript.



This phase of the project has been enriched by the collective expertise, insights, and dedication of our team and the hard work of our students. We are deeply grateful for the time, effort, and thoughtful contributions that each of you has invested in supporting this work. Your responsiveness, engagement, and commitment have been invaluable in moving these outputs forward.

We are focusing on refining and strengthening these resources through targeted consultations with individual team members. We look forward to continuing this collaborative process as we work toward the completion and dissemination of these important knowledge mobilization products that will all be in a toolkit hosted by the Africa Albinism Network.

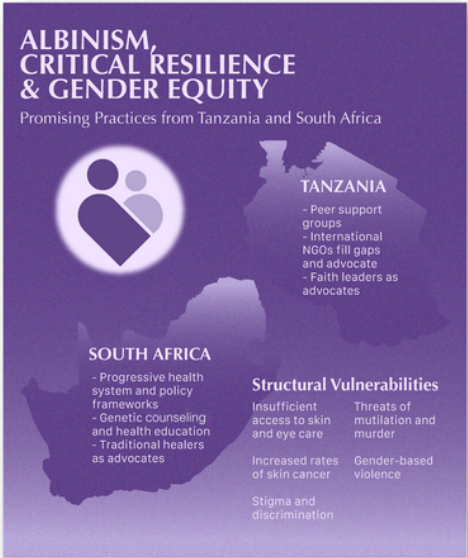
THANK YOU!

Publications

Writing and knowledge generation continue to be a central part of our work. We are pleased to share some of our 2026 publications featuring the leadership and collaboration from members of our research team. As we move further into the knowledge mobilization phase of the project, we welcome and encourage team members who are interested in contributing to future manuscripts to connect with Sheryl, Barb, Shirley, and IK. We look forward to continuing to share our collective learning and impact through scholarly publications.

A comparative analysis of the critical resilience and gender equity of mothers impacted by albinism: Promising practices from Tanzania and South Africa

This paper provides an overview of our earlier project on *Mothering & Albinism* with comparative findings from Tanzania and South Africa. We highlight practices that promote and protect human rights through equity, community, and resilience.



Reading gender through lived experiences of albinism in South Africa: A feminist analysis

Using our SSHRC data from South Africa, Sonya Sharma, Innocentia Mgijima-Konopi, and Sheryl Reimer-Kirkham, with TWU PhD candidate Karen Larochelle, wrote about mothers' experiences through a gendered lens.



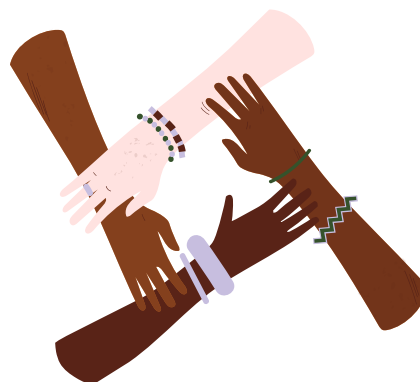
Curriculum resources for integrating respectful maternity care into health professions education: A rapid scoping review

Central to the birth experience of mothers and their babies with albinism is their experience with healthcare providers. Led by Kendra Rieger, our nurses and midwives conducted a scoping review of how healthcare providers are taught Respectful Maternity Care.



GRANTS AND FUTURE WORK

The Birthing Stories project is yielding rich findings and expanded partnerships. We are keeping our eye out for grant opportunities to further this work, especially with knowledge mobilization projects to scale up the Toolkit. In June, we submitted an application to the CIHR Planning and Dissemination call and partnered with Africa Albinism Network for an application to Together Women Rise. We anticipate we will continue to be competitive for funding from Canada's Tri-Council funding agencies. We invite team members to let us know as other funding opportunities come to your awareness.



Congratulations!

We are excited for Innocentia Mgijima-Konopi in her new position as Senior Officer, Alliance Strengthening and Member Support, with the International Disability Alliance!



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 (PH/CA); Karen Larochelle (CA); Tumisho Mokwele (SA); Emma Strobell (CA); Ingrid Watts (CA)

