



Report: Engagement Workshop 2023

A Human Rights and Equity-Oriented Response to the Birth Stories of Families Impacted by Albinism in Sub-Saharan Africa: Intersectoral Partnerships for Enhanced Health Professions' Education

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Background



The *Mothering and Albinism* research-advocacy-policy network are embarking on research to improve mothers, families, and carers' experiences during the birth of a baby with albinism through health access and health professions education in Africa and Canada. The first year of four has been focused on hosting an Engagement

Workshop and conducting a Participatory Systematic Review (literature synthesis) on birth stories on albinism of mothers and their carers.

The Workshop was hosted through coordinated efforts between Trinity Western University (Canada), University of Pretoria (South Africa), and the Africa Albinism Network, along with participating partners. The Workshop brought together our team comprised of advocates, health professionals, educators, policymakers, and academics, from various corners of the globe, in a series of multisectoral and transdisciplinary engagements which occurred on 02 to 04 October 2023 in Pretoria, South Africa. Conference Chair Innocentia Mgijima-Konopi, University of Witwatersrand, moderated the three days.



The purpose of the Engagement Workshop was to bring together our intersectoral network to:

- Facilitate the engagement of all stakeholders in decision-making about the Birthing Stories project,
- Generate/build knowledge about the project focus,
- And deepen contextual awareness of albinism in Africa and Canada.

The synergy of intersectoral collaboration and the collective wisdom gained during the Workshop will give momentum to the 4-year project as we commit to improving experiences and outcomes for mothers, families, and birth attendants when a baby with albinism is born.

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Dr. Barbara Astle (Project co-lead), Trinity Western University, Canada

Ikponwosa Ero (Project co-lead, virtual attendance), Africa Albinism Network, Canada

Project Team:

Dr. Mary Ani-Amponsah (virtual attendance), University of Ghana, Ghana

Dr. Lydia Aziato, University of Ghana, Ghana

Dr. Lori Beaman, University of Ottawa, Canada

Dr. Maretha de Waal (virtual attendance), University of Pretoria, South Africa

Duncan Dixon (virtual attendance), Trinity Western University, Canada

Dr. Bonny Ibhawoh, McMaster University, Canada

Dr. Elvis Imafidon, SOAS University of London, England

Dr. Jennifer Kromberg, University of Witwatersrand, South Africa

Dr. Michael Lang, Mike Lang Stories, Canada

Dr. Ronell Leech, University of Pretoria, South Africa

Nomasonto Mazibuko, Albinism Society of South Africa, South Africa

Innocentia Mgijima-Konopi, University of Witwatersrand, South Africa
Dr. Muluka-Anne Miti-Drummond, UN Office of High Commission for Human Rights, Geneva
Dianah Msipa, University of Pretoria, South Africa
Dr. Lillian Ohene, University of Ghana, Ghana
Dr. Eunice Pallangyo, Aga Khan University, Tanzania
Dr. Kendra Rieger, Trinity Western University, Canada
Perpetua Senkoro, Tanzania Human Rights Defenders Coalition, Tanzania
Dr. Sonya Sharma (virtual attendance), University College London, England
Dr. Landa Terblanche (virtual attendance), Trinity Western University, Canada
Dr. Wisdom Tettey, University of Toronto, Canada
Mpho Tjope, Albinism Advocacy for Access, South Africa
Dr. Boateng Wiafe, Operation Eyesight, Ghana

Stakeholders:

Kwame Andrews Daklo (virtual attendance), Africa Albinism Network, Ghana
Caroline Nothando Dlamini, mother of child with albinism, South Africa
Merlyn Glass, Genetic nurse counsellor, South Africa
Tshego Keitsemore, Reamogeleng Community Organization, South Africa
David Sithole, father of child with albinism, South Africa
Lorraine Tshuma, We Are People Foundation, South Africa

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Nazifa Rashid (virtual attendance), University of Toronto, Canada
Cole Siebert (virtual attendance), Trinity Western University, Canada
Adzeglo Tugbe (virtual attendance), University of Ghana, Ghana

We thank the guests of the workshop:

- Mariska Van der Walt, Deputy Director, Disability Rights, Gauteng Office of the Premier, South Africa
- Phuti Mabelebele, Chief Director, Advocacy and Mainstreaming Rights of Persons with Disabilities, Department of Women, Youth and Persons with Disability in the Presidency, South Africa
- Patrick Wadula, Chairperson, National Albinism Taskforce, South Africa
- Janet Gbam, University of Pretoria, South Africa
- Monica Araujo, Genetic Counsellor at National Health Laboratory Service, South Africa
- Mukhethwa Audrey Mavhungu, University of Pretoria, South Africa

We are also grateful to the artists who shared their art:

- Athenkosi Kwinana, South Africa
- Adebayo Okeowo, South Africa
- Patricia Willcoq, Congo

With gratitude to many South African colleagues who contributed to the success of our Workshop:

- Innocentia Mgijima-Konopi (Conference Chair)
- Dr. Ronell Leech (organizer Day 2, University of Pretoria)
- Dr. Dianah Msipa (assisted with the logistics)
- Emihle Majikija (assisted with the logistics)
- Stacey Mgijima (assisted with the logistics)
- Sabeeha Majid (assisted with the logistics)
- Puleng Molebatsi (co-hosted public forum)

In memory of team member Dr. Maxwell Thabethe and community researcher Busisiwe Mahlaba.

Introduction

The first day of the conference provided background and introduced the team to the *Mothering and Albinism* project, which included engaging in a Public Forum. To set the pace for the conference, the first day began with an internal meeting attended by all project team members who were participating in the conference. The meeting was led by **Dr. Sheryl Reimer-Kirkham** and **Dr. Ramadimetja Shirley Mooa**. They facilitated introductions, gave a brief history of the *Mothering and Albinism* research project, and took us through an overview of the Engagement Workshop.

Ikponwosa Ero, inaugural United Nations Expert on the enjoyment of human rights by persons with albinism and one of the project's co-lead of the *Mothering and Albinism* project, contributed to this segment with a recapitulation of the historical developments that have led to this moment in *Mothering and Albinism* research and advocacy. She reminisced about the initial engagements with Drs. Reimer-Kirkham and Astle which kick-started the formation of the Mothering and Albinism project. In her virtual address, she talked us through a 'Global Mapping of the Albinism Movement', highlighting that although much progress has been made in improving the realities of persons with albinism globally, there remains much room for improvement. She applauded the work that continues to be done under the auspices of the *Mothering and Albinism* network as a significant part of this work and recognised the multisectoral approach of this project as a vital ingredient of our success in the producing knowledge, raising awareness and driving change in the albinism movement through research that informs policy.

Muluka-Anne Miti-Drummond, the current United Nations Expert on the enjoyment of human rights by persons with albinism then spoke about the current developments of the albinism mandate. As she unpacked the mandate and vision of her office, Miti-Drummond drew attention to the work done by mothers of children with albinism in protecting their children and championing their welfare. She highlighted her March 2023 Report wherein she asserted the urgent necessity for mothers of children with albinism to be recognised as human rights defenders

even though they may not adopt that title for various reasons.¹ Miti-Drummond shared that her upcoming work expands on Ero's work in advancing the enjoyment of human rights by persons with albinism in their pursuit of education. She further highlighted an upcoming Report from her office that will focus on the experiences of persons with albinism in education, adopting a region-specific approach as the experiences of persons with albinism in education are not universal but reflective of regional nuances. Given the focus of the *Mothering and Albinism* project, an interesting development to anticipate is another upcoming Report from the UN expert that will look into the human rights situation of children with albinism who *do not* enjoy parental care or guardianship. She highlighted the United Nations [video](#) on mothers and children impacted by albinism.

Panel 1: A Conversation on the Albinism Movement

In the build-up to the Public Forum, a panel discussion was held with human rights defenders who themselves are persons with albinism in Tanzania, South Africa, and Ghana. On the panel were Perpetua Senkoro (Tanzania), Commissioner Nomasonto Mazibuko (South Africa) and Mpho Tjope (South Africa) with Kwame Andrews Daklo joining the conversation virtually from Ghana. The panellists shared country-specific insights concerning the human rights framework for persons with albinism, the legislative interventions for the protection of persons with albinism, the situation of mothers and children impacted with albinism in terms of access to services, as well as the best practices from their respective organisations.

Commissioner Nomasonto Mazibuko and **Mpho Tjope** shed light on the albinism advocacy landscape in South Africa. They highlighted persisting issues around employment discrimination, the need for rights-respecting lexicon to be developed in vernacular languages, attacks against persons with albinism driven by superstition and criminality as well as limited access to resources such as sunscreen and skin cancer screening. They both stressed the establishment of the National Albinism Task Force, in recent years, as a game-changing intervention

¹ A/HRC/52/36, M. Miti-Drummond 'Human rights defenders working on albinism: Report of the Independent Expert on the enjoyment of human rights by persons with albinism' 09 March 2023 <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G22/614/03/PDF/G2261403.pdf?OpenElement> accessed 04 October 2023.

that has strengthened advocacy efforts by bringing together otherwise dispersed movements under the banner of a single task force. By uniting diverse organisations in the pursuit of common goals, the Task Force has enabled the growth of the albinism movement in South Africa as cross-pollination on leadership, strategies and resources has amplified the voice of persons with albinism. One of the notable gains of the National Albinism Task Force is the development of the National Action Plan which also speaks to the situation of mothers impacted by albinism. Another is the availability of transport for persons with albinism to be able to access healthcare interventions such as vision and skin cancer screenings which they otherwise be excluded from due to lack of awareness and financial constraints.

Perpetua Senkoro highlighted that the Tanzanian experience is similar to that of South Africa. Their approach has been marked by education campaigns and engaging government, youth, and communities to remove the stigma and raise awareness of albinism. Best practices from Tanzania include the provision of higher education scholarships and securing dignified work placements for persons with albinism. With this, it has been observed that employers are becoming increasingly responsive to employing persons with albinism. Another win from Tanzania is the practice of providing entrepreneurship training and seed money for mothers affected by albinism to counter the limited access to services and sunscreen through entrepreneurship. To address the accessibility of services and resources along a rural-urban divide, mobile clinics are used to provide visual screening and skin cancer screening in even the most remote parts of the country. The challenges faced by persons with albinism that warrant advocacy, support and government intervention are those related to the waves of violence against them. Placing emphasis on the need for sustaining momentum beyond the attacks, Senkoro impressed the need for sustained awareness campaigns, for cross-thematic action plans that collate advocacy work in each country into a single voice, and for ‘champions’ of intersectoral collaboration to be identified - individuals to spearhead the collaborations.

Kwame Andrews Daklo joined the conversation virtually to comment on the Ghanaian experience. There remains much work to be done to end the stigma and discrimination against persons with albinism and their families in Ghana. Community education initiatives have been essential to their advocacy work but harmful beliefs and practices still persist. In some rural communities, persons

with albinism are prohibited from entering and residing due to traditional beliefs and discrimination and exclusion from basic services persist.

Public Forum

The Public Forum (co-hosted by the National Albinism Task Force, Albinism Society of South Africa, Albinism Advocacy for Access, Africa Albinism Network, the School of Health Care Sciences and Centre for Human Rights at the University of Pretoria, and Trinity Western University) was a resounding success with stakeholders from various countries in the global and local albinism sphere. The program was guided by Puleng Molebatsi, a media practitioner and mother with albinism and Innocentia Mgijima-Konopi. Approximately 75 individuals attended the forum, comprising of persons with albinism, mothers of children with albinism, advocates, government officials, health professionals, and researchers.

The overarching purpose of the Public Forum was to present and deliberate on the findings and recommendations of the *Mothering and Albinism* research team at the nexus of research, advocacy and policy in the South African context. The Public Forum was geared towards:

1. Engaging all stakeholders, especially persons with albinism, on observations emerging from our research on best practices in supporting mothers and children affected by albinism;
2. Creating a forum for bringing the voices of mothers impacted by albinism and activists into the dissemination of the information;
3. Raising awareness on the experiences of persons with albinism, affected mothers and families; and
4. Supporting the mandate and vision of the United Nations Expert to protect and promote the rights of persons with albinism.

Principles of Engagement and Method of Work

Engagements and dialogue throughout the forum were guided by the necessity of centralising the experiences of mothers and families affected by albinism. It was, therefore, a priority to ensure that all participants made contributions which were oriented around the recommendations of the South Africa Report, rallying behind

the common goal of enhancing the well-being and security of persons with albinism and their families.

The Public Forum began on a high note as **Commissioner Nomasonto Mazibuko** led the room in song and gave a warm welcome to conference attendees. As a person with albinism herself, the Commissioner's opening speech resounded the significance of the role played by mothers of children with albinism in empowering and instilling in them the confidence that enables them to defy odds and pursue their illimitable and fulfilled lives.

Presentation 1: Human Rights and Albinism

Although most African countries are signatories to the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), the Convention has been criticised for not sufficiently taking the African context into account while the regional instruments are also criticised for not sufficiently taking disability into account. Scholars have also noted the gaps and limitations of existing human rights legal frameworks at global and regional levels to achieve full inclusion for persons with disabilities.

In the first part of this presentation, **Dr. Dianah Msipa** examined how the African Disability Protocol (hereafter, 'the Protocol') responds to the unique experience of disability discrimination faced by persons with disabilities in Africa. She highlighted the Protocol as an appendage to the African Charter for Human and Peoples Rights which exemplifies such a culturally relative framing of disability rights interventions that address disability discrimination issues in context. Experiences of albinism are not universal but shaped by regional nuances. Therefore, human rights responses must reflect this. The Protocol addresses this in several aspects. Firstly, the Protocol makes specific reference to issues such as 'ritual killings'.² Secondly, Articles 9 and 11 of the Protocol place an obligation on State Parties to take action towards the eradication and punishment of practices of concealment and confinement of persons with disabilities whereby parents hide/conceal the birth of their child- depriving them of identification documents and the many opportunities which that would avail. Thirdly, it makes reference to albinism as a disability and it provides a broader understanding of disability

² African Union, 'Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa' https://au.int/sites/default/files/treaties/36440-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf Accessed 02 October 2023

rights by expressly listing ‘disability’ as a distinct ground for discrimination in addition to improving the situation by including the denial of reasonable accommodation.

Dr. Bonny Ibhawoh advanced the vernacularisation of human rights as a key avenue towards advancing the human rights of persons with albinism in Africa. Framing the rights of people with albinism within the broader human rights context would require a critical interrogation of the integration of African Customary Law into the practice of human rights. The Protocol mentions the integration of customary law as a mode of access to justice for persons with albinism. Considering that African customs and traditional beliefs do not always exist in complete harmony with human rights, bringing human rights into the local context must include the rights-affirming aspects of African traditions. Another way in which human rights can be translated into the local context is through the inclusion of traditional African philosophies as South Africa has done in advancing the philosophy of Ubuntu into human rights discourse. It was evident that the discussion concerning the vernacularisation of human rights made a resounding impact. He also drew attention to the five outstanding ratifications that are still required for the African Disability Protocol - a call to action for civil society actors to engage State Parties towards the ratification of the Protocol - taking action to operationalise the strengths of the human rights framework for persons with albinism in the African region.

Presentation 2: Mothering and Albinism South Africa Video Premiere

The *Mothering and Albinism* research team premiered a short film, featuring mothers with albinism and mothers of children with albinism in South Africa. The film was produced by Puleng Molebatsi of Puleng Molebatsi Media House. The film highlighted how mothers are human rights defenders and claimants, emphasizing how their resilience is fostered through health education and support from peers, NGO/CSOs, and grants such as the disability grant. Molebatsi and the mothers who shared their stories in the short film were present as the video premiered to resounding applause and glowing reviews.

The “Mothering and Albinism in South Africa” video is a wonderful example of how human rights and the arts can be a formidable combination to shift the focus from the instruments of human rights advocacy and protection to centre the experiences and voices of mothers and children impacted by albinism as human

experiences - rightfully emphasising the lived realities of real people rather than portraying them as abstract anecdotes that are vaguely drawn from in research and only notionally dealt with in legislation and policy.

The video can be accessed [here](#).

Presentation 3: The Mothering and Albinism South Africa Report

The team's South Africa Report was released at the Public Forum to support mothers and children impacted by albinism and their families. The Report drew from a research study conducted by the *Mothering and Albinism* team. It provides guidance in interventions ranging from social responses and advocacy, policy development and access to resources for mothers and their children.

Dr. Jennifer Kromberg began the presentation by sharing some important facts about albinism in the global and South African context. She emphasized that albinism is a group of conditions caused by a genetic mutation. She drew attention to the fact that the occurrence of albinism has been recorded in most countries in the world, yet the availability of data on the estimated prevalence rates of albinism by country stands at a staggering 13% with only 36 out of 193 countries reporting data on the frequency of albinism, and African countries accounting for 40% of known statistics. Physical features that would generally be considered as phenotypic markers of albinism tend not to draw as much attention in the European context as fair skin and hair is not uncommon. Thus the attendant ocular conditions that are a manifestation of the genetic inheritance of albinism are oftentimes treated as stand-alone visual conditions with no relation to albinism. This is understood to be a significant factor in the under-reporting of albinism occurrence in that region, which was flagged as a research gap for future investigation. Dr. Kromberg discussed ongoing work and areas where further research is needed, including studies on topics like skin cancer risk, fertility issues, life expectancy, intellectual development outcomes, paternal studies, the effectiveness of genetic counselling services, and cultural factors influencing perceptions within communities affected by albinism.

Dr. Sheryl Reimer-Kirkham, lead of the *Mothering & Albinism* network, highlighted that taking a multisectoral and interdisciplinary approach with a diverse representation of countries and regions has been at the core of *Mothering and Albinism* from the ideation stages of the network in Geneva in 2018.

Stakeholders involved in the South African data collection process included community researchers, healthcare professionals, civil society, teachers and policy-makers. The overarching aim of the research outputs is to amplify the voices of the mothers - making the ‘lofty’ more relevant to the local by producing accessible educational and advocacy tools that enable action and solutions from a strength-focused perspective. The recommendations in the Report are arranged and communicated in accordance with the intended audiences. For instance, a recommendation is made for birth attendants to affirm the baby, educate the mother, and involve the father at birth. In essence, the recommendations are to serve as guidelines at every step of the mothering experience, for all stakeholders. As all stakeholders pull their weight towards fostering resilience and supporting mothers along the way, the Report, pamphlet, and video will serve as advocacy and education tools, guidelines on how to enforce government accountability, and information directories so that mothers know how to seek help and peer support.

The Report can be accessed [here](#).

Dialogue: Commentaries from Mothers Affected by Albinism

True to the overarching goal of amplifying the voices of mothers impacted by albinism, we were honoured to have three mothers join us to lead a conversation on their experiences.

Tshego Keitsemore is a mother of a child with albinism whose mothering experience has had a tremendous impact on the person that she is and how she serves her community. Living in a community that was fraught with discrimination, myths and stigmatisation presented many challenges in her parenting journey. Prompted by the encouragement of a nursing practitioner whom she encountered during her subsequent pregnancy, her journey in albinism activism began with the inception of a support group where other affected mothers and Reverends came together to advocate for children and young mothers who were affected by the widespread discrimination against people living with albinism and their families. Today, she is a pillar of support for mothers and children impacted by albinism in the Northern Cape to the extent that her participation in the conference was cut short by an emergency call from back home. One of the healthcare centres in the Northern Cape which came to know of her work as a support group leader and albinism activist under her organization, Reamogeleng Community Organisation, requested her urgent

intervention when a young mother who had just given birth refused to accept her baby who had just been born with albinism.

Thembisile Madlala (founder of Albinism Society KZN) is a mother with albinism whose activism predates her mothering experience. When her pursuit of education opportunities was frustrated by the stigma and discrimination against persons with albinism, she resolved to form a support group in 1998, using Ukhozi FM, a South African radio station as a channel. This platform extended her reach to places near and far across KwaZulu Natal as she engaged with persons with albinism, community leaders, traditional leaders, and various other stakeholders. Inspired by the level of government support in the cause of Albinism awareness and advocacy, she returned home with a vision to cultivate those civil society-government relations in South Africa. Her narration of her birthing and mothering experience aptly captured the human essence of the challenges faced by mothers impacted by albinism, which are often couched in lofty technical terms from human rights to the health sciences. She related how upon the delivery of her child in a public facility, the reaction of the birth attendants was less than felicitous. Nurses turned to her husband to incite rumours of infidelity being the cause of their child being born with albinism despite herself being a person with albinism. Her experience also highlights the lack of genetic education, especially in rural and traditional communities. A key contention raised by Thembisile is the rural-urban divide and varied prioritisation of reasonable accommodation and access to services for persons with albinism across provinces.

Lorraine Tshuma (We Are the People Foundation) is a career woman, entrepreneur, and activist. Through her South African foundation, she works primarily with the albinism community, providing support and encouragement and walking the journey with parents and children who are affected by albinism. She cited her spiritual connection as the driving force behind her commitment to doing good, assisting families to navigate the social, emotional and health journey of raising a child with albinism. Drawing from her birthing and mothering experience, Lorraine spoke to the challenges that mothers experience in the spheres of education and dignified healthcare for persons with albinism. Lorraine shared that despite having had the privilege of giving birth in a private healthcare facility, she was unable to escape the unkind and traumatic treatment to which mothers impacted by albinism are subjected. She highlighted that her experience

is cushioned by the financial and other resources that her education, eloquence and urban life afforded her. She emphasised the need for higher education for healthcare and education professionals that intentionally incorporates disability-responsive and -respecting curricula to unseat negative attitudes and superstitions which continue to undercut access to adequate and dignified healthcare and education for persons with albinism. Lorraine further stressed the government to be held accountable for their failure to deliver basic needs such as sunscreen to all persons with albinism.

Dialogue: Stakeholders' Commentaries

This panel truly animated the human side of the challenges that the recommendations made in the Report are crafted to address.

Muluka-Anne Miti-Drummond kickstarted the panel discussion on the note of “putting the ‘human’ back into ‘human rights’”. Miti-Drummond lauded the conference for grounding deliberations in a human-centred approach as it veers away from discipline or practice-specific jargon towards accessible language which speaks to the goal of listening to the stories of mothers impacted by albinism. She remarked that the stories shared were an inch in the right direction - to inform discussions and reinforce reality-responsive approaches from all stakeholders, including her mandate. The lack of access to essential healthcare information is an unjust limitation of the full enjoyment of human rights by persons with albinism.

Dr. Ramadimetja Shirley Mooa affirmed the concerns of the previous panel concerning the failure to incorporate albinism-responsive and human rights-sensitive content in healthcare professionals' education.

Mariska Van der Walt (Deputy Director: Disability Rights, Gauteng Office of the Premier) commented on the use of vernacularised or simplified resources such as pamphlets, citing educational resources of the National Albinism Taskforce as instrumental in her work as well. She applauded the albinism movement in South Africa for the formation of the National Albinism Taskforce as a development that has strengthened government engagement with the albinism movement in South Africa.

Phuti Mabelebele (Chief Director: Advocacy and Mainstreaming Rights of Persons with Disabilities, Department of Women, Youth and Persons with Disability in the Presidency) began by highlighting that her office is mandated to coordinate service delivery by ministerial offices in the cabinet, with a key function being the oversight of the creation of plans of action for the Department of Health. The implementation of programs and interventions to support persons with disabilities depends on alignment across cabinet portfolios which encumbers access to services and complicates the process for civic actors who wish to hold public officials accountable for the persisting administrative failures, such as the provision of quality sunscreen and other healthcare interventions for persons with albinism.

Patrick Wadula (Chairperson, National Albinism Taskforce South Africa) highlighted the progress that the Taskforce has achieved since its inception. He welcomed the focus of the Mothering and Albinism Report on access to healthcare and the critical need for education to enhance the quality of life for persons with albinism from birth and well into adulthood. He further stated that the National Action Plan of the Taskforce does already speak to such challenges. He closed by issuing a clarion call to potential donors to engage the Taskforce further to unlock progress in these very critical areas for mothers and children impacted by albinism, especially for the aid of those whose access to resources is blocked by the rural-urban divide.

The panel discussion ended on a high note with a robust question and answer session which highlighted the slow progress of holistically addressing disability rights in South Africa. Most inquiries were directed towards Department of Women, Youth and Persons with Disability in the Presidency as delegates sought to understand how persons with albinism are prioritised in a portfolio that also includes Women and Youth as specific categories, the categorisation of albinism as a disability for the purpose of disability welfare support, and the status of albinism as a disability for employment equity purposes under the Employment Equity Act. Apparent from those engagements was that bureaucracy and disharmony in terms of the mandates and approaches of different sectors within the South African government pose a challenge to the progress of the albinism movement in the country.

Day Two: Tuesday, 03 October 2023
**Venue: Department of Nursing Science, Faculty of Health Sciences,
University of Pretoria, Pretoria**

Dr. Ramadimetja Shirley Mooa initiated the conference proceedings for the day with a warm welcome to the University of Pretoria.

Panel 2: Birthing, Albinism, and Africa and Canada

Dr. Mooa prompted the panel of experts in nursing science, Dr. Lydia Aziato (Ghana), Dr. Ronell Leech (South Africa), Dr. Victoria Nesengani (South Africa), Dr. Lillian Ohene (Ghana), Dr. Kendra Rieger (Canada) and Dr. Eunice Saity-Pellangyo (Tanzania) to give an overview of the birthing process including the context when mothers give birth through traditional birthing practices, and how mothers can access healthcare and Respectful Maternity Care in their respective countries.

Dr. Lydia Aziato noted the challenges relating to lack of privacy in birth settings as well as the issue relating to autonomy which are vital components to comprehensive Respectful Maternity Care. She also noted that much emphasis and authority is afforded to doctors and obstetricians in maternal care and decision-making, especially in public hospitals. Midwives acknowledging and honouring the autonomy of their patients and implementing Respectful Maternity Care remained limited as midwives themselves are unable to act with autonomy in the current hierarchy. About albinism, she described her experience when she encountered a mother who gave birth to a child with albinism in a private facility. The mother was referred to an ophthalmologist and a dermatologist. She shared that from the Ghanaian government, there is no available support for mothers but they may find assistance with NGOs or churches that provide some support.

Dr. Ronell Leech gave an overview of the regulation of nursing education in South Africa and the different educational pathways that exist to gain entry into practice as a clinical midwife. The focus of the midwifery component is women-centred and primary health care incorporating counselling and health teaching. She gave key inputs into the incorporation of Respectful Maternity Care in nursing education and practice following the principles outlined by the World Health Organization to promote positive health experiences incorporated in midwifery education. She also noted that nurse education in South Africa does

equip them to respectfully navigate the religious, traditional, and cultural diversity of South Africa. She observed that there is no formal collaboration with traditional birth attendants but recognizes the importance of traditional medicine and practices, ensuring that they are appropriate and safe. At the moment, Respectful Maternity Care has not been formally incorporated into the mainstream nursing curricula.

Dr. Victoria Nesengani shared insights on birthing and albinism in Africa. Dr. Nesengani pointed out that the bifurcation of the healthcare system was not unique to the Tanzanian experience, but a shared reality with South Africa. She described that the healthcare system is divided into two: the public and private sectors. She shared that the public healthcare system caters to the needs of most South Africans, placing much emphasis on the existence of the maternal obstetric clinics which involve advanced midwives in providing antenatal care and assisting in low-risk deliveries where there is a need. When there is an increased need that requires further intervention, they are referred to the public hospital. There are also health providers who are traditional healthcare workers or birth attendants and independent midwives.

Dr. Lillian Ohene from Ghana pointed out that there remains a gap in Ghanaian nursing practices and nursing curricula in integrating Respectful Maternity Care. There are several workshops that are attended by nurses and midwives on a regular basis across the country, discussing what Respectful Maternity Care is and how they can apply it to their practice. She pointed to research findings that draw a correlation between the inability of public nurses to successfully implement Respectful Maternity Care practices in Ghana with disproportionately high patient volumes. Traditional birth attendants were being trained by midwives, especially in preventing infections. Respectful Maternity Care is not part of the teachings, but most women turn to traditional and spiritual birth attendants because they are provided with individualised care; they are given one-on-one care. Addressing albinism in Ghana, she described that midwives experience anxiety upon receiving the baby: “How do I break this news to the mother?” It is seen as a disability at birth. Nurses or midwives who have genetic knowledge will engage with the mother about family history to prepare her to receive the news. Support will then depend on the mothers’ socioeconomic status in what they are able to access.

In Tanzanian birthing practices, **Dr. Eunice Saity-Pellangyo** highlighted that socioeconomic status plays a huge role in the determination of who gets to access high-quality obstetric and gynaecological care. The quality of healthcare is disproportionately divided between mothers who are subjected to the severely under-resourced public healthcare system versus those that can access private healthcare. She emphasised the need for further education of midwives as they play a significant role in childbirth to close the gap caused by poor quality of care in the public facilities, specifically as it concerns the nursing practices that cater for the needs of people living with disabilities such as albinism. The practice of traditional birth attendants has not been acknowledged in the healthcare system, but the practice suggests that there are people who are assisting mothers giving birth. Moreover, she described that Respectful Maternity Care is a relatively new concept in Tanzania and the integration is limited in higher education. It has been acknowledged that mothers experience disrespect that affects the care provided to them.

Dr. Kendra Rieger described maternal care in Canada, noting that many deliveries in Canada take place within the hospital setting under the care of medical doctors through the publicly funded Canadian healthcare system, with only 13% of births being attended by a midwife. Midwifery is a relatively new regulated profession in Canada but is in high demand. The mechanism in place to provide health care for mothers in rural or remote settings, especially Indigenous communities is not without its challenges. The process involves relocation of the mother to a healthcare facility that is located elsewhere outside their community, introducing the challenge of isolation from family and community in the already challenging delivery and post-delivery period. Resources and health teachings are provided postpartum including videos that coincide with the education provided. Public health follows up with all patients except for mothers followed by midwives, ideally after 48 hours of being discharged. In regards to Respectful Maternity Care, labour and delivery nurses may not have heard of the term but there are concepts that relate to it such as family-centred care.

Dr. Maureen Musie (midwifery lecturer, University of Pretoria's Department of Nursing Science) delivered a presentation on the integration of traditional birthing practices into mainstream health care, and albinism in South Africa. Drawing on the findings of her PhD study, Dr. Musie shed light on the role of traditional birth attendants in primary obstetric health care in South Africa. She

highlighted that traditional birth attendants found in Gauteng spanned a range of categories including prophetic faith healers, traditional healers, child healers and traditional birth attendants. As one of the key themes discussed throughout the conference concerned the decolonisation of birthing practices and the need to debunk myths surrounding the births of children with albinism, Dr. Musie's discussion of the regulation of traditional birthing practices through the Traditional Health Practitioners Act as well as the Traditional Health Organisation South Africa was timely and relevant to the discussions as she concluded by emphasising the need for respectful maternity care practices by way of traditional birth attendants as one of the ways to improve birthing experiences for mothers who birth children with albinism.

Merlyn Glass, a nurse genetic counsellor, described that parents who are carriers of the gene will have a 1 in 4 chance of having a child with albinism. In South Africa, 1 in 30 black Africans carry the albinism gene. Because the albinism gene is identifiable, the genetics clinic receives families who had a baby with albinism and would like to know what the chances are of having another baby with the same condition. Parents would like to be informed as some are expecting to have a child with albinism. She stated that genetic counselling is available in South Africa and includes on-call services. She explained that genetic services help patients understand and adapt to the medical, psychological, and familial implications of the genetic contribution of a condition. During their appointments, genetic counsellors assist in identifying the family history of albinism and other possible genetic conditions. They engage in discussions so that families can make informed decisions. They also provide support by making referrals to dermatologists and ophthalmologists as well as antenatal clinics. Genetic counselling involves educating families to dispel myths and debunk stigmas that have painted albinism as anything other than a genetic condition.

Dr. Elvis Imafidon gave a presentation titled An African Perspective on Corporeality (understanding the body) and Birthing Stories. On the one hand, we have the biology of a body but on the other hand, we also have corporeality norms; these are values to the facts that we perceive (i.e., race, able bodied-ness). He highlighted that there is a dichotomy between facts and norms, descriptions of who we are. His contribution to the discussion of human rights-responsive, decolonised and respectful maternity care, highlighted the need for the ambivalent nature of the health practitioner's conception of the body to be centred

in the education of healthcare professionals. He called for the deliberate inclusion of the medical humanities and medical linguistics in particular, to challenge the insidious normative coding which reproduces harmful social norms as negative attitudes and harmful clinical practices against persons with disabilities such as albinism.

Panel 3: Human Rights and Higher Education

In the third panel, we heard from Dr. Lori Beaman (CA), Janet Gbam (SA), Dr. Bonny Ibhawoh (CA), Dr. Ramadimetja Shirley Mooa (SA) and Dr. Wisdom Tettey (CA) as they engaged in a conversation about higher education, human rights and albinism.

Dr. Ramadimetja Mooa spoke about decolonisation in higher education. She emphasized that education does not come just from academia but that there are various ways of knowing and different ways of teaching. The definition of decolonization in higher education will depend on the context; the idea is to debunk what colonisation brought to the knowledge arena. In academia, she highlighted the challenges in the acknowledgment of recognising other knowledge bearers like her grandmother and other women in her village. She pointed to her unique experience as both a clinical and traditional nurse who is active within academia as an example of how mainstream nursing academia reinforces its monopoly on knowledge by excluding traditional ways of knowing as quality academic sources and theories that are worth citing in research. She emphasized the need for openness and contextualizing how we teach to integrate culture and practices.

Janet Gbam, a PhD candidate at the Centre for Human Rights, University of Pretoria, spoke about inclusive human rights education for tertiary institutions. She highlighted the following: (1) Ensuring each individual's human rights, and in this case, persons with disabilities, including persons with albinism can only come when we come together; (2) In curriculums, we must aim to humanize human rights; (3) We must vernacularize human rights in a way that an ordinary person can interact with it, and not just seeing it as an abstract concept. (4) We must acknowledge that there are intersectional issues in human rights, such as the intersectionality of gender, colourism, and other identities. In her study where she

reviewed the human rights curriculum of twelve institutions across Africa, disability rights were not applied in the context of albinism. She highlighted mainstream human rights in tertiary education and making human rights law accessible to the layperson to inspire civic engagement and ownership of the causes espoused in disability rights law.

Dr. Lori Beaman gave an engaging talk where she unpacked the concept of *deep equality* in the context of albinism. She called for the emphasis on human rights-led approaches to the birthing experiences of mothers who birth children with albinism, to be coupled with the vernacularisation of human rights and the inclusion of other approaches that draw from everyday actions and stories that reflect moral and ethical codes. An insight shared here was that whilst human rights in a silo will not change attitudes nor go a long way in humanising persons with disabilities, a complementary approach that also invokes storytelling as an agent of change can be more effective in achieving deep equality.

Dr. Wisdom Tettey added to the conversation by turning to a discussion of the representation of persons with albinism in discourses within the media. He described that albinism in the media is mainly in the African context, and it focuses on the tropes associated with albinism. An example he described was the coverage of witchcraft in Africa in relation to albinism. He emphasized the importance of studying media representation because in order to understand a phenomenon, one must first understand what has given birth to those representations. Public discourses are the milling ground for things that become essentialized ideas about who people are and how people should be treated. Media has been a mechanism in which discussions have been propagating such as African movies with particular connotations on albinism, seeing persons with albinism as mythical. He described that the media can be used for good to evoke the changes we aim to see but it also holds the kinds of tropes and stereotypes that give vent to the experiences we hear. He called for a rethinking of the lexicon used in popular discourses on persons with albinism. He urged for particular attention to be paid to the continual use of degrading and dehumanising lexicon in media and public discourse as it has a significant role to play in the othering of persons with albinism.

Dr. Bonny Ibhawoh focused his discussion on how the conversations within the albinism movement and disability movement inform broader conversations about

human rights. He emphasized that although we might think that the struggles faced by persons with albinism are individualized including for those involved such as health providers working in the health sectors with persons with albinism, the struggle actually pertains to the whole of human rights. He highlighted the term ‘melanin privilege’, which Dr. Elvis Imafidon had introduced, as an example of rights-respecting and condition-specific language which now we all benefited from that could be useful for the development of effective human rights law instruments. The conversations and vernacularisation on various aspects affecting persons with albinism have had a global/universal impact and expanded the notions of human rights. Although we have universal rights, there are certain communities that need special protection. He shared that the disability as well as the albinism human rights movement is teaching the international human rights community on the complementarity between domestic complications and International obligations; he shared that although the duty is on the state, there is also international responsibility.

Panel 3: Enhancing Services for Persons with Albinism and Families

The final panel is on enhancing services for persons with albinism and their families with discussions from Dr Boateng Wiafe, Meghann Buyco, Tumisho Mokwele, Monica Araujo, and Mukhethwa Audrey Mavhungu.

In his presentation, **Dr Boateng Wiafe** gave a talk on access to eyecare for persons with albinism. He spoke about the different visual impairments that persons with albinism experience, depending on the type of albinism one has, which included decreased vision function, nystagmus and strabismus. Although there is no cure for albinism, he described the various interventions applicable to improve the vision of persons with albinism such as prescription eyeglasses, absorptive sunglasses, and surgery for eye alignment. He highlighted barriers such as lack of education/awareness, poor trust in healthcare providers, and expensive treatments correlate to the decrease access to vision care. A notable contribution from his talk is the necessity of early-age intervention for children with albinism as vision improvements are possible until mid-teens.

Tumisho Mokwele presented a systematic review she conducted on existing literature on community responses to children born with albinism, which is part

of her PhD studies. She shared that albinism is still poorly understood in community settings which contributes to the stigma, discrimination, name-calling and social isolation faced by persons with albinism. This reality often occurs across different cultures across Africa. There is limited education and awareness of albinism among community members. Some mothers hide their child and the birth of a baby with albinism is not celebrated. Her findings echoed that of Dr. Lori Beaman's call for an integrative approach that views human rights perspectives in tandem with everyday experiences within one's own community. She highlighted the need to address the structural inequities to promote social integration and access to basic services. She emphasized the need to challenge harmful beliefs and look to other guidance including through the Ubuntu way to accept persons with albinism.

Meghann Buyco then presented her findings from her master's in nursing thesis on siblings impacted by albinism in Africa. She spoke about how the unique vulnerabilities and the stigmatisation due to harmful beliefs and practices affect not only persons with albinism but their parents and siblings as well. She described that siblings also experience discrimination and stigma by association with having a sibling with albinism. In addition to their parents, siblings provided support to each other including providing access to basic daily necessities, education, and healthcare. She shared that siblings are impacted upon the birth of a baby with albinism, that they too may be confused and they may also need support including health education about albinism. Buyco's research supports the call for a family-centred approach to albinism advocacy and for supporting persons with albinism and other disabilities.

Monica Araujo spoke about the availability of genetic counselling in South Africa. Access to these services depends on the healthcare providers who know about genetic services. She acknowledged that many families may not have such referrals due to healthcare providers who are unaware of these services to provide to the mother and the family or that healthcare providers have misinformation about what genetic services entail. Other barriers to genetic services include the long distances and lack of financial resources. They encountered some mothers who knew about genetic counselling while some have not and relied on the internet for information. Genetic counselling also involves the psychosocial aspects of albinism. She described that some people had negative connotations to persons with albinism such that they are spectacles. Araujo emphasized that

nursing and midwifery students must be educated on genetic knowledge to help educate communities and prevent the spread of misinformation.

Mukhethwa Audrey Mavhungu, a final year nursing student at the University of Pretoria, added to the genetic service availability in South Africa. Mavhungu described that genetic counselling is beneficial for families to make informed decisions about their pregnancy and medical interventions. She discussed the disparities within the South African healthcare system that impedes access to quality healthcare in the birthing experiences of persons affected by albinism such as the expenses relating to skin and eye care, accessibility and availability of services, and the negative social attitudes, cultural belief systems, and systemic biases.

Dr. Barbara Astle delivered a presentation on the emerging scientific field of Planetary Health. Building on an earlier publication on climate change, the well-being and human rights of persons with albinism, Dr. Astle called for a transdisciplinary, equity-centred approach to ensure the health of the global community and planetary conservation to support effective public and policy implementation. Identifying persons with albinism as particularly structurally vulnerable to the health effects of climate change (i.e., increased risk for developing skin cancer), she advanced an equity-centred approach to be prioritised. A fundamental shift in how universal health care is delivered at the primary level necessitates systemic changes globally. This major shift includes a stark acknowledgment of how people and human systems (social determinants of health) interact in shaping the interplay of the attainment of the highest level of human health and the state of the planet's natural systems. She called on societal transformation, promotion of developing economies, and prioritization of planetary health.

Dr. Sonya Sharma gave a virtual presentation on the global developments in gender and religion, critically discussing how the privileging of gender and religion as foremost in the construction of identity eclipses class, race, and disability. Drawing from post-colonial feminist approaches and feminist critical race theorists, Dr. Sharma discussed the nuances of the identity of a woman who is a mother. She suggested an intersectional framing of 'mothering'/motherhood that does not uncritically eclipse the intersectionality of a woman's identity by positing one aspect of her life - playing the role of a mother - as the most definitive, whilst also allowing her the liberty of identifying with the role of mother as an essential part of her identity should she choose.

Dr. Michael Lang delivered a presentation on digital storytelling, a person-centred video production methodology that directly involves storytellers throughout the entire process. He described stories can travel and it can influence, beliefs, attitudes and values which in turn influence behaviours. He shared a previous digital storytelling project that touched and motivated his audience to work with communities in solving health problems. His project influenced policy at a national level. Digital stories can start meaningful discussions and he emphasized that even one story is powerful. Some video production

methodologies have more potential to collect and share video-based stories in an ethical and compelling manner. He described that digital storytelling helps vernacularize human rights to promote the health and wellness of persons with albinism. It also integrates local languages, knowledge, and customs of individuals in the film; they drive the conversation through their stories. Finally, he emphasized that digital storytelling promotes sharing, a direct and fast action for audiences to take part in.

To wrap up conference proceedings, the team embarked on an experiential activity at Dr Mabena's Traditional Healing Gardens, an international award-winning nature conservation and indigenous healing practice situated on the outskirts of Pretoria, where the group was treated to an immersive tour of a South African Sangoma and herbalist practice.

A final team dinner at the Blu Saffron Restaurant deepened our team relationships and celebrated our success.

*Many thanks, dankie, and ngiyabonga to our South African colleagues
for their amazing hospitality!*