



MOTHERING & ALBINISM

Newsletter: Summer 2023

We hope you and yours are well.

We are grateful for our collaborative transdisciplinary team. Having you as part of our team has enriched our project to make positive social changes to improve the experiences of families affected by albinism in Africa.

Project Updates

Mothering, albinism and human rights in Africa: Mapping patterns of resilience at the juncture of gender, colourism, and religion

Funding: Social Sciences and Humanities Research Council Grant, 2019-2023 (SSHRC #435-2019-1120)

With the end of our data collection for the ***Mothering and Albinism project***, we have submitted completion reports to all our HREBs from this grant. Thank you to all our colleagues who have supported this phase, including Lori Beaman, Bonny Ibhawoh, Wisdom Tettey, Diana Msipa, and Emma Strobell. We are immersed in the last phase of knowledge translation and final project outputs. The South African team is finalizing a Report with recommendations to support mothers and children affected by albinism in South Africa. Accompanying this Report, we are working with Puleng Molebatsi, a person with albinism herself in South Africa, to create a short film featuring mothers with children with albinism, mothers with albinism, and key stakeholders. Puleng and her crew are currently filming in Benoni, Johannesburg,

and Northern Cape. We are grateful to the mothers, Jennifer Kromberg, Merlyn Glass, Mpho Tjope, Nomasonto Mazibuko as well as Puleng and her team. The Report and video will be released during our Workshop in South Africa in October 2023.



We are also working on final papers which include a methodology paper, a paper on birthing stories, and a comparative paper.

A human-rights and equity-oriented response to the birth stories of families impacted by albinism in Africa: Intersectoral partnerships for enhanced health professions' education

Funding: Canadian Institutes of Health Research Grant, 2022-2026 (CIHR #481405)



We are currently on Phase I (of 4) of our **Birthing Stories project**. As you know, we will be gathering together in Pretoria, South Africa in October 2023 for an Engagement Workshop. We are looking forward to learning and having many fruitful and meaningful discussions, laying the groundwork for this new project.

For those who are not in South Africa, you will have received a formal invitation letter through email. We will be sending additional details, such as the final detailed schedule in September.

Also in Phase I, a subgroup of our team members has been working on a participatory systematic review on birthing experiences of mothers, families, and birth attendants in sub-Saharan Africa. We met regularly to inform each step of our systematic process and engaged mothers impacted by albinism as key stakeholders. We are now in the data extraction phase using NVivo, a data management software. We will be validating the findings with the team during our Workshop. We will be sending materials prior to our meeting in October.

Student Internship

In May 2023, we began accepting applications for student internship. We were pleasantly surprised by the number of students who were interested in this opportunity. Thank you to everyone who shared the application with your students in your universities. We are excited to introduce to you our six interns for 2023:

- Rebecca Kyeraa Amankona (GH)
- Emmanuel Osei (GH)
- Adzeglo Tugbe (GH)
- Kiel Mayich (CA)
- Nazifa Rashid (CA)
- Cole Siebert (CA)

Over the next year, they will be working alongside our team members in supporting our research on birthing stories.

ICN Congress 2023



In July 1-5, 2023, Sheryl Reimer-Kirkham, Shirley Mooa, Barb Astle, Lydia Aziato, Victoria Nesengani, Kendra Rieger, and Meghann Buyco, along with Trinity Western University's PhD Nursing students, attended the biennial International Council of Nurses Congress. About 6,000 nurses from more than 130 countries attended the conference in Montreal, Canada. We presented our research project through a presentation and three e-posters. You can read more and view the e-posters on our blog. Please [click here](#).



Prevalence of Albinism Worldwide

During our team meeting on March 21, 2023, Jennifer Kromberg presented on a systematic review on the prevalence of albinism worldwide. We are delighted to congratulate Jennifer and her colleagues for publishing their article titled “[Determining a Worldwide Prevalence of Oculocutaneous Albinism: A Systematic Review.](#)”

Thesis on Albinism and Siblings



For Meghann Buyco's final project for her masters in nursing, she conducted a study on exploring the experiences of siblings impacted by albinism in Africa through dyad interviewing. She successfully defended her thesis on June 27, 2023. She wrote her reflections in a blog: please [click here](#).

To read her full thesis, please [click here](#).

Looking forward to seeing you on our next full team meeting on August 31st, 2023.

Project Team



Sheryl Reimer-Kirkham (CA)

Barbara Astle (CA)

Ikponwosa Ero (CA)

Shirley Mooa (SA)

Mary Ani-Amponsah (GH)

Lydia Aziato (GH)

Lori Beaman (CA)

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 Akorfa 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)

Tshego Keitsemore (SA)

Lorraine Tshuma (SA)

Emma Strobell (CA)

Meghann Buyco (CA)

Tumisho Mokwele (SA)

Ingrid Watts (CA)

Jessica Wilson (CA)

Blog www.motheringandalbinism.com

To see a complete list of team publications, please [click here](#).