



MOTHERING & ALBINISM

Newsletter: SPRING 2022

Happy New Year! Acknowledging the impact of the COVID-19 pandemic, we bring this newsletter to you with hope for what lies ahead and with deep appreciation for your continued support and engagement to this project.

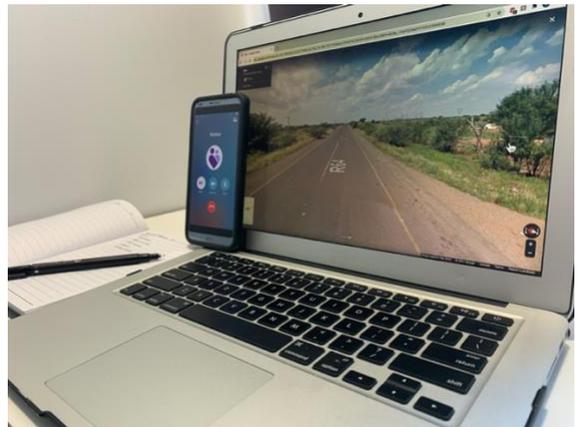
Announcements

African Union Plan of Action (2021-2031)

Based on its precursor, the Regional Action Plan to end attacks and discrimination against people with albinism (2017-2021), the African Union Plan of Action to End Attacks and other Human Rights Violations Targeting Persons with Albinism (2021-2031) was developed by the United Nations Independent Expert on the rights of persons with albinism and adopted by the Executive Council of the African Union. The Action Plan enumerates achievable goals and actions to foster participation among all actors and stakeholders and promote accountability at a national level. The activities presented address the key concerns faced by persons with albinism in areas of security, health, social, and economic spheres.

To view the full report, click [here](#).

Project Fieldwork



We are resuming virtual fieldwork in Northern Cape and Gauteng provinces of South Africa in 2022, with a focus on key stakeholders. We interviewed a genetic counsellor with ample experience with mothers affected by albinism. Facilitated by Dr. Kromberg, we gained insights particular to genetic counselling such as genetic testing during prenatal visits and obtaining genetic counselling, especially after birth. In collaboration with Innocentia Mgijima-Konopi, Busisiwe Mahlaba (cultural liaison/research assistant) will interview five more mothers. With the constant shifts concerning the pandemic, we continue to watch for South Africa news updates and trust on the expertise of our on the ground partners.

Knowledge Translation in Tanzania: Faith Leaders' Summit

In partnership with Perpetua Senkoro (Knowledge Translation Facilitator, TZ), Kondo Seif (Knowledge Translation Facilitator, TZ), and Reverend Cannon Thomas Godda (Executive Director, Interreligious Council for Peace Tanzania), we completed four consecutive virtual interreligious Faith Leaders' Summits in Tanzania from November 27, 2021 – January 22, 2022. The seminars were held in Swahili, and the Canadian team were able to access translation in the background using the Zoom interpretation feature with Tanzanian partners Diana Leonard and Annabahati Gwacha. Marco Methuselah (St. Paul's Theological Seminary, Mwanza) and Sheikh Kabeke (Mwanza) presented on faith teachings related to human rights and albinism. Other Muslim and Christian faith leaders from diverse backgrounds participated to discuss practices that best protect and promote the rights of mothers impacted by albinism in Tanzania. Mothers from *Upendo wa Mamas*, a support group in Tanzania for mothers affected by albinism, were present during the four seminars. Their engagement was important as they were able to voice their concerns and participate in developing strategies with the faith leaders. Proceeding from the Summit, the faith leaders created a final statement and strategized an action plan. The statement was presented to the Director of Disabilities on February 6, 2022 in Dodoma. A media release is forthcoming to profile the recommendations of the Faith Leaders.

Knowledge Translation in Tanzania: Film Project

To present the perspectives of mothers during the Faith Leaders' Summit, we created a short film featuring two mothers impacted by albinism from the *Upendo wa Mamas* group in Tanzania. We worked with a Tanzanian filmmaker, Ezekiel Mkusa, who filmed and composed the video. Perpetua Senkoro was

featured in the film, assisted in organizing this project, and provided the English subtitles. The aim for the film is to use storytelling as a way to communicate with the public, while centering the voices of mothers. We shared the process of creating the video in our blog [here](#). You are welcome to use the film for educational purposes and would welcome suggestions on how to use the film to further highlight mothers impacted by albinism.

The video is available on [YouTube](#).

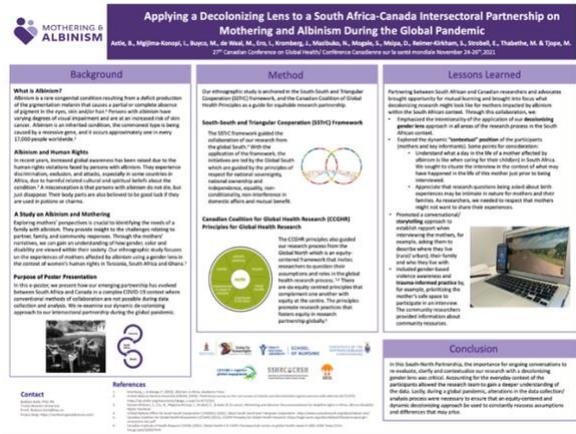
Witchcraft Resolution Commentary

In July 12, 2021, the United Nations Human Rights Council adopted the resolution: The Elimination of Harmful Practices related to Accusations of Witchcraft and Ritual Attacks. This resolution acknowledges concerns to harmful practices of witchcraft and ritual attacks that have led to various forms of violence against people in vulnerable situations including women, children, and persons with disabilities with specific mention of persons with albinism. It was proposed in 2017 at a United Nations Experts Workshop on Witchcraft and Human Rights organized by Ikponwosa Ero (former Independent Expert on the enjoyment of human rights by persons with albinism), Dr. Charlotte Baker (Lancaster University), Gary Foxcroft (Director of WHRIN), and Kirsty Brimelow (international human rights barrister). The Lancaster University published a short article, which you can read [here](#).

In response to this resolution, we have written a commentary (publication pending) describing how the resolution relates to our project. From our data, mothers impacted by albinism bear the disproportionate burden of human rights violations because they have albinism themselves or have given birth to children with albinism. They are stigmatized, threatened, and/or attacked and they have constant worry of their safety and of their children's due to harmful practices. With the resolution recognizing the rights to freedom of thought, conscience and religion while acknowledging the enjoyment of all human rights and

fundamental freedoms, mothers impacted by albinism can speak of their experiences in the context of acceptable and non-acceptable cultural practices.

Poster for the Canadian Conference on Global Health



poster overall by the attendees. The South Africa and Canadian team is moving into the next phase of drafting a manuscript to further describe this Africa-Canada intersectoral partnership. To read more about the e-poster, please visit our blog [here](https://www.mothingandalbinism.com).

Team Updates



During the Canadian Conference on Global Health for the Canadian Association of Global Health on November 24-26, 2021, the South Africa team (Innocentia Mjijima-Konopi, Jennifer Kromberg, Nomasanto, Mazibuko, Maxwell Thabethe, Mpho Tjope, Dianah Msipa, Maretha De Waal, and Shirley Mogale with Sheryl Reimer-Kirkham, Barbara Astle, I.K. Ero, Emma Strobell, and Meghann Buyco) presented (virtually) an e-poster on applying a decolonizing lens to a South Africa-Canada intersectoral partnership during the global pandemic from our mothering and albinism project. The e-poster was well received, reaching the fourth highest viewed

As of January, Emma Strobell transitioned out of her role as project coordinator and is taking on a more casual position as research assistant. She has taken full time work as a Practice Consultant with a local Health Authority but looks forward to remaining connected to the ongoing project work.

Going forward, Meghann Buyco will be the main contact.

Blog www.mothingandalbinism.com

Project Team

- Sheryl Reimer-Kirkham (CA)
- Barb Astle (CA)
- IK Ero (CA)
- Lori Beaman (CA)
- Bonny Ibhawoh (CA)
- Elvis Imafidon (NI/UK)
- Jennifer Kromberg (SA)
- Innocentia Migijima-Konopi (SA)
- Nomasanto Mazibuko (SA)
- Perpetua Senkoro (TZ)

- Sonya Sharma (UK)
- Wisdom Tettey (CA)
- Boateng Wiafe (GH))
- Maxwell Thabethe (SA)
- Mpho Tjope (SA)
- Dianah Msipa
- Maretha De Waal (SA)
- Shirley Mogale
- Emma Strobell (CA)
- Meghann Buyco (CA)

- Faith Leaders**
- Kondo Seif (TZ)
 - Reverend Cannon Thomas Godda (TZ)