



MOTHERING & ALBINISM

Newsletter: Summer 2022

As we approach our summer months here in Canada, we wish to express our gratitude for your continued support to the albinism project.

Announcements

International Albinism Awareness Day 2022

The theme chosen by the United Nations to celebrate the International Albinism Awareness Day 2022 was “United in Making Our Voice Heard.” The theme was chosen to celebrate how the groups of people with albinism and individuals have increased the visibility and of persons with albinism and to encourage unity among people living with albinism.

Project Fieldwork

Virtual fieldwork continues in South Africa where we heard from mothers impacted by albinism connected with a genetic clinic in Johannesburg. These interviews were facilitated by Jennifer Kromberg and Merlyn Glass. The mothers shared important perspectives on the access to health services, particularly health education during the

postnatal period. We are currently interviewing additional stakeholders (thanks to Innocentia, Nomasonto, Jenny, Shirley, and IK for these connections).



We are in the beginning stages of virtual fieldwork in Ghana, beginning with two stakeholders active in the albinism community.

Mother's Day

For this year's Mother's Day, the African Albinism Network (AAN) hosted a webinar highlighting mothers impacted by albinism. The virtual event was hosted by Kwame Andrews Kaklo (Ghana) and featured our team member Perpetua Senkoro (Tanzania). It was to celebrate the mothers' resilience as well as the unwavering love they have for their children. They shared their lived

experiences as mothers impacted by albinism and had open conversations about the stigma and discrimination that they faced and overcame.

To watch the full video, we linked it in our blog, [click here](#).

Access to Health for Mothers Impacted by Albinism in South Africa

Amnesty International Southern Africa Regional Office has developed the first journal on Albinism in Southern Africa called the *Southern African Albinism Journal* (congratulations to Innocentia as the first editor of the journal). The journal focuses on the Economic, Social and Cultural Rights (ESC Rights) of persons with albinism. It seeks to foster a greater understanding of the inequalities and discrimination that persons with albinism in Southern Africa face in the realization of their ESC rights; how these have been accentuated in the context of the Covid 19 pandemic; the impact thereof and recommendations to address these issues. The South Africa team (Innocentia Mgijima-Konopi, Jennifer Kromberg, Nomasonto Mazibuko, Maxwell Thabethe, Mpho Tjope, Dianah Msipa, Maretha De Waal, Shirley Mogale, Sheryl Reimer-Kirkham, Barbara Astle, Emma Strobell, and Meghann Buyco) was invited to write a paper on the access to healthcare for mothers impacted by albinism in Southern Africa. We drew from our South Africa data to describe their experiences, highlighting the challenges they faced in accessing vision and skin care and health education about albinism. We will circulate the article when published.

Article in Journal of Global Health

In response to the 2021 UN Resolution on the elimination of harmful practices, the team published a viewpoint (commentary) article on the applications of this resolution to mothers impacted by albinism. The Open Access article is available [here](#).

Ophthalmology Educational Event: Vancouver, Canada

On May 20, 2022, Ikponwosa Ero and Barb Astle were the Keynote Speakers at the International Joint Commission Accreditation on Allied Health Personnel in Ophthalmology (IJCAHPO) in conjunction with the British Columbia Society of Eye Physicians and Surgeons Program at an Educational Regional Event in Vancouver, BC, Canada. IJCAHPO provides continuing education and certification for Allied Ophthalmic Personnel (comprised of Ophthalmic Assistants, Ophthalmic Technicians, Ophthalmic Technologists, and Registered Nurses). Our presentation was entitled: *Contributing to a Global Human Rights Movement for Persons with Albinism: A Research-Policy-Advocacy-Network*. IK provided background about her United Nations (UN) mandate as the former Independent Expert to the Human Rights Council at the UN, followed by articulating why this is a human rights issues and how allied health professionals, ophthalmologists and optometrists can provide visual care for persons with albinism. Barb presented on the trajectory of our research in Tanzania: our scoping review findings; the development of our Delphi Survey culminating in the September 2018, Human Rights and Albinism: Research-Policy-Advocacy Roundtable in Geneva around sharing our collective priorities and building research capacity; our Mothering and Albinism research; and the shift to virtual data collection due to the global pandemic as we moved to South Africa; and concluding with some final recommendations from our research.



Health Policy Residency

Barb Astle and Sheryl Reimer-Kirkham were teaching a health policy residency with 20 TWU graduate MSN students at the end of May at TWU's Laurentian Leadership Centre in Ottawa, Canada (our Nation's Capital). See photo below.



Ikponwosa Ero joined us virtually for a seminar on June 2nd, to talk about her leadership in the albinism human rights movement. The students remarked on IK's leadership philosophy and strategies (e.g., of community engagement), and learnt about the relationship between health policy and human rights.



Grant Update

The Mothering & Albinism team submitted a Canadian Institutes of Health Research (CIHR) grant application "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" on March 16th, 2022. We expect to hear funding results in the middle of July.



We are looking forward to seeing you at our next Full Team Meeting on August 30th, 2022.

Blog www.motheringandalbinism.com

Project Team

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