



# MOTHERING & ALBINISM

## Newsletter: Spring 2023

We are excited to bring you this newsletter to welcome the team members who have joined us on *Mothering and Albinism*! The newsletter is circulated two/year and posted to our [blog](#).

### Announcements

#### AAN Forum 2023



(Photo credit: [AAN](#))

The Africa Albinism Network (AAN) is a consortium of organizations working to promote through human rights advocacy, the dignity, rights, and welfare of persons with albinism and their family members. AAN was founded in 2021 by the former UN Independent Expert on the enjoyment of human rights. by persons. with albinism,

Ikponwosa Ero. On February 7-9, 2023, AAN hosted the AAN Forum 2023 in Dar es Salaam, Tanzania. The main objective for the event was to develop the capacities of 36 albinism groups from across 13 countries (Angola, Benin, DRC, Kenya, Madagascar, Malawi, Mali, Mozambique, South Africa, Tanzania, Togo, Uganda, and Zambia) to develop their skills and enhance coordination to use the AU Plan of Action (2021-2031) as a tool for albinism advocacy within their countries.

### 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)

As of November 2022, we have concluded data collection in Tanzania, South Africa, and Ghana. We sincerely appreciate the assistance from our team members in recruiting and connecting us with our participants. We also express our deepest appreciation to all our participants,

mothers and stakeholders, who have been so gracious and entrusted us with their stories.



We have commenced in the process of sharing our cumulative findings by working on academic papers as well as a knowledge mobilization project in South Africa by way of a report and video.

### **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 one of four in exploring the birthing stories of families impacted by albinism in sub-Saharan Africa. Recently, we engaged in a meaningful and insightful discussion through a *Birthing Stories Circle* with stakeholders, mothers who have given birth to a baby with albinism (Tshego Keitsemore and Lorraine Tshuma), NGO/CSOs on albinism and have worked closely with families impacted by albinism, and birth attendants like nurses and midwives, to guide and inform our search strategy in conducting a participatory systematic review. To read more about the Birthing Stories Circle, please [click here](#). Onto the next step: we are working closely with a librarian, Duncan Dixon, to identify relevant literature, reports, and other sources that give insights to the experiences of mothers, families, and birth attendants during the birth of a baby with albinism in Africa.

## **Engagement Workshop**

In October 2-4, 2023, we will be hosting an Engagement Workshop at the University of Pretoria, South Africa to gain a collective understanding of the context of birthing, albinism, and Africa, to inform the next phases of this research project, and to build relationships among our team. Kindly **RSVP by February 28<sup>th</sup>, 2023** whether you are able to attend.

## **Intern Opportunities**

We are thrilled that we are able to include undergraduate and graduate students during our research processes. Each year, we have intern opportunities, three from Africa and three from Canada. We welcome students from any field of discipline. If you know of a student who may be interested, application and details will soon follow.

## **Climate Change and Albinism**

Led by Barbara Astle, we published an article entitled Global Impact of Climate Change on Persons with Albinism: A Human Rights Issue with the *Journal of Climate Change in Health*. Climate change has been a rising global issue, and in this paper, we discussed how climate change significantly and uniquely impacts persons with albinism through a disability and human rights lens. The article is open access and available [here](#).

## **ICN Congress 2023**



On July 1-5, 2023, the International Council of Nurses (ICN) will be hosting this year's international gathering. In Montreal, Canada.

Given the number of nurses on our team and the international reach of ICN, our team will be highlighting the incredible insights from our project through four presentations/ e-posters. To learn more about the ICN Congress 2023, please [click here](#). Here are the details for the accepted abstracts:

### **Access to Healthcare in Tanzania and South Africa**

Drawing from our cumulative findings from Tanzania and South Africa, led by Sheryl Reimer-Kirkham, we will be presenting on the insights from mothers and stakeholders regarding access to healthcare, highlighting the lack of health information on caring for a child with albinism; and inaccessibility of services such as genetic counselling, skin care, and vision care.

### **Moral Emotions in Caring for Children with Albinism in South Africa**

Led by Shirley Mooka and Victoria Nesengani, in an e-poster and discussion session, we will present two themes, a) trepidation and b) compassion, as two types of moral emotions experienced by mothers caring for children with albinism, revealing the need for the provision of psychosocial services for mothers and their children with albinism.

### **Nurses Leading an Intersectoral Transdisciplinary Partnership**

An e-poster on our intersectoral transdisciplinary partnership will be presented during the ICN Congress which will be led by Barbara Astle. We will describe the formation of the project to support the United Nations Independent Expert mandate in protecting and promoting the rights of persons with albinism.

### **Family-Centred Approach in Supporting Siblings Impacted by Albinism**

An e-poster will also be presented on implementing a family-centred approach to support siblings impacted by albinism in Africa. Meghann Buyco will be drawing from her thesis

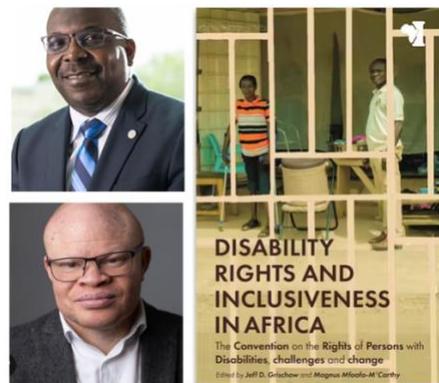
to foreground the need to ensure support for families impacted by albinism.

### **Knowledge Mobilization: Respectful Maternity Care**



Graduate nursing student, Ingrid Watts, is currently working on her knowledge mobilization project on respectful maternity care. In March 2023, she will be hosting a virtual engagement session with our nursing team members in Africa to share her findings from her synthesis and engage in a dialogue about how this applies in nursing education in the context of Africa. Ingrid's KT project is part of the groundwork for the Birthing Stories research project.

### **Chapters in the *Disability Rights and Inclusiveness in Africa***



Congratulations to Bonny Ibhawoh and Elvis Imafidon for their chapters in a new volume, [\*Disability Rights and Inclusiveness in Africa: The Convention on the Rights of Persons with Disabilities, Challenges and Change\*](#) (Edited by Jeff Grischow and Magnus Mfofo-M'Carthy; Published by Bodell and Brewer). Bonny's chapter is titled "Framing Disability Rights within the African Human Rights Movements" and Elvis's chapter is titled "African Ontology, Albinism, and Human Rights".

## 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)  
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**Blog [www.motheringandalbinism.com](http://www.motheringandalbinism.com)**

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