

Below we list *a small but growing fellowship of scholars / researchers* (not listed in any particular order) who have made contributions to the topic of albinism in various African countries.

Abbreviation – PWA (person with albinism)

Ms. Ikponwosa “I.K.” Ero, MA, JD, ik.ero@unalbinism.org

<https://www.ohchr.org/EN/Issues/Albinism/Pages/IkponwosaEro.aspx>

Designated in June of 2015 as the first UN Independent Expert on the enjoyment of human rights by persons with albinism. The vision of Ms. Ero’s mandate is driven by the cross-cutting principle of the UN Sustainable Development Goals: “leaving no one behind...starting with the furthest behind first.” Ms. Ero has over a decade of experience in research, policy development, and practice of human rights concerning persons with albinism. She has advised organizations and governments around the world on human rights concerning persons with albinism. As the International Advocacy and Legal Officer for Under the Same Sun -- an international organization with a focus on albinism -- she developed strategic initiatives involving regional and international human rights mechanisms, prepared guiding documents, and oversaw the implementation of recommendations made by the UN and other human rights organizations. Ms Ero is also the author of numerous papers and articles, particularly with regards to the applicable legal frameworks as well as the development and implementation of special measures to facilitate the enjoyment of human rights by persons with albinism. In her capacity as Independent Expert, I.K. was chosen for UNESCO's List of 70 Who-is-Who of Women Speakers across the world to celebrate UNESCO's 70th anniversary in 2015. She was also recently named in NewAfrican Magazine’s list of 100 most influential persons of 2017.

- ***To see reports*** from the mandate on various themes **CLICK HERE:**

<https://www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx>

- ***To monitor the situation*** and observe the implementation of the Action Plan on the continent of Africa, go to this link and then click on the “Implementation” tab. You can also click on the “Library” tab for other resources: <https://actiononalbinism.org/>

Dr. Sheryl Reimer-Kirkham & Dr. Barb Astle:

SHERYL REIMER-KIRKHAM PhD, RN - Sheryl.Kirkham@twu.ca

Professor | School of Nursing

Member | College of New Scholars, Royal Society of Canada

Trinity Western University | t: 604.513.2121 (3239)

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BARBARA ASTLE, PhD, RN – Barbara.Astle@twu.ca

Associate Professor | School of Nursing

Director | Centre for Equity and Global Engagement (CEGE)

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Sheryl and Barb, along with Graduate Research Assistants, Kristi Panchuk and Emma Strobell, conducted an extensive research project related to the effects of spiritual/cultural beliefs on the social and health wellbeing of persons with albinism. The site for the multi-country research on ***Mothering and Albinism*** is completed along with some publications of findings. ***Click here to visit the site.*** You may also follow the project on Twitter:

@MomsAndAlbinism. In September of 2018, their research team lead a Roundtable on Human Rights and Albinism in conjunction with the 39th session of the United Nations Human Rights Council in Geneva. The first event of its kind, this meeting brought together 32 scholars, decision-makers, and advocates from ten countries to set a clear direction for field research on the human rights abuses suffered by people with albinism - <https://www.twu.ca/news-events/news/leading-united-nations-roundtable-human-rights-and-albinism>

Dr Elvis Imafidon; Nigerian professor of Philosophy and also a person with albinism:

Department of Philosophy,
Faculty of Arts,
Ambrose Alli University, Nigeria.
2017 Fellow, JIAS.

Editor, Ewanlen: A Journal of Philosophical Inquiry

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LINKEDIN: <https://www.linkedin.com/profile/view?id=263756896>

BOOKS:

Elvis Imafidon (Ed.), Handbook of African Philosophy of Difference (Springer 2019).

<https://www.springer.com/gp/book/9783030148348>

Elvis Imafidon. African Philosophy and the Otherness of Albinism: White Skin, Black Race (Routledge 2018)

<https://www.routledge.com/African-Philosophy-and-the-Otherness-of-Albinism-White-Skin-Black-Race/Imafidon/p/book/9781138335400>

Elvis Imafidon & John A. I. Bewaji (Eds.), Ontologized Ethics: New Essays in African Meta-ethics (Lexington Books, 2013)

<https://www.amazon.com/Ontologized-Ethics-Essays-African-Meta-Ethics/dp/0739185039>

Elvis Imafidon (Ed.), The Ethics of Subjectivity: Perspectives since the Dawn of Modernity (Palgrave Macmillan, 2015).

<https://www.amazon.com/Ethics-Subjectivity-Perspectives-since-Modernity/dp/1137472413>

Elvis Imafidon, The Question of the Rationality of African Traditional Thought: An Introduction (CreateSpace 2013)

<https://www.amazon.com/Question-Rationality-African-Traditional-Thought/dp/1494373319>

FORTHCOMING TITLES:

Elvis Imafidon & Björn Freter (Eds.), Handbook of African Philosophy: Key Subject Areas

Noel Estrada-Hernández, PhD, CRC

Department Executive Officer

Associate Professor of Rehabilitation and Mental Health Counseling

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Noel, a Puerto Rican man with albinism himself, is also an academic who counsels, researches and writes on the topic of albinism, including an article titled “Psychological Aspects of Physical Difference: The Experiences of Eight Adults with Albinism in Puerto Rico” published in JVIB - Special issue on albinism and vision
<https://www.afb.org/afbpress/newpubjvib.asp?DocID=jvib1206toc>

Stephen Robinson - Photographer

wildfoto@wildfotoafrica.com / bcr@wildfotoafrica.com

Photo documentary: Life in the Shadows: Albinism in Africa - the unknown story of the everyday lives of those living with albinism in Africa

- o https://www.google.ca/?gfe_rd=cr&ei=BN29V9zYBNHM8geBjLPgBg&gws_rd=ssl#q=Life+in+the+Shadows:++Albinism+in+Africa

Giorgio Brocco - gbrocco85@gmail.com

PhD Candidate
Funding: DAAD
Freie Universität Berlin
Institute of Social and Cultural Anthropology

His completed work in 2015: One is entitled "Labeling albinism: Language and discourse surrounding people with albinism in Tanzania", while the second is called "“People with albinism and humanitarian NGOs: Identities between local and global worlds.”

<http://www.tandfonline.com/eprint/iUgU6cjtstBJAYGXZhRr/full>
<http://www.medizinethnologie.net/?p=468>.

His completed work in 2016: One deals with life experiences, subjectivity and stigma related to albinism in a rural area within the Iringa region, while the second paper intends to analyze the relationships between music and albinism.

<http://www.tandfonline.com/doi/full/10.1080/13648470.2016.1184009>
<http://www.medizinethnologie.net/singing-albinism-in-global-tanzania/>

Emily Urquhart, PhD Emily.urquhart@gmail.com emily.urquhart@mun.ca

Book release March 31, 2015

Book Title: *Beyond the Pale: Folklore, Family and the Mystery of Our Hidden Genes*,
Published by Harper Avenue; ISBN 978-I-44342-356-4

Emily Urquhart is a Canadian author who did her PhD in Folklore. Her dissertation was on albinism and she has now turned her research into a book. What got her going was giving birth to her first child in 2010, a daughter with albinism. It’s a great read for first time parents of a child with albinism but goes way past parenting to research the history of albinism worldwide, including what’s going on in Tanzania / Africa. Part of her

research took place in Tanzania, East Africa. Since folklore is her forte, it's all written in story form.

Cora Butler-Jones, PhD CPnkldy@aol.com

Book release March 2015

Book Title: *The Bones and Resilience of A Person with Albinism: The Impact of Help-Seeking Behavior Among People With albinism In Tanzania*; Tate Publishing and Enterprises, LLC; ISBN 978-1-63418-774-9

Dr. Butler-Jones is a lecturer, college professor, and mother of two daughters. She is very interested in gene-related anomalies such as albinism and has a particular interest in Tanzania where a significant part of her research for the writing of this book took place.

Dr. Patricia Lund p.lund@coventry.ac.uk / apx251@coventry.ac.uk

Principal Lecturer: School of Life Sciences

Albinism in Africa project

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<https://pureportal.coventry.ac.uk/en/persons/patricia-lund>

You may recognize my name as having worked with families with albinism (over 20 years now!) in South Africa, Zimbabwe, Malawi and Zambia. The information leaflets (including one for teachers), stories, newsletters etc. generated on my projects are all freely accessible at: <https://pureportal.coventry.ac.uk/en/persons/patricia-lund>

The information leaflets on albinism are available by clicking on the links below:

[Information for children](#)

[Information for teachers & parents](#)

My current project involves using radio and SMS to train teachers and communities around albinism issues in Malawi and Zambia: Integrating community and media networks to promote educational inclusion of children and young people with albinism. I am planning to extend this work to other English speaking countries in sub-Saharan Africa.

Dr Charlotte Baker c.baker@lancaster.ac.uk

I am a lecturer at Lancaster University in the UK. My research interests focus on the literary representation of albinism, but I am also interested in different explanations of albinism. My book *Enduring Negativity: Representations of Albinism* is developed from my PhD thesis, written at Nottingham University. (Charlotte Baker, *Enduring Negativity: Representations of Albinism in the Fictional Work of Didier Destremau, Patrick Grainville and Williams Sassine*. Oxford: Peter Lang, 2011. ISBN: 9783034301794)

Michele Burlot micheleburlot@gmail.com

I have worked for over a dozen years in humanitarian assistance prior to my graduate studies at St. John's University in New York pursuing a Master's degree in Global Development & Social Justice. As part of this program, I completed a Capstone Project titled *Applying Stigma Reduction Best Practices to the Problem of Stigma and Violence towards People with Albinism in Tanzania*.

Dr. Simeon Mesaki simeonmesaki@yahoo.com Cell: +255 713 407 625.

Currently practicing in the Department of Sociology and Anthropology, University of Dares Salaam, Tanzania. He wrote his Ph. D thesis, "Witchcraft and Witch-killings", at the University of Minnesota in 1993.

Alex Alum a-alum2010@nlaw.northwestern.edu (201) 232-8206

In March of 2009, I traveled with two classmates, Edilsa Ruiz and Michael Gomez, to Tanzania to research the killings of persons with albinism. We were law students at Northwestern University of Law in Chicago, Illinois. The results of our research are a 2 page abstract and a research paper (attached) called "Hocus Pocus, Witchcraft, and Murder: The Plight of Tanzanian Albinos.

Tom McLeod t.mcleod@ucl.ac.uk

A medical student in UK who just completed his dissertation (attached) on PWA in E. Africa. His research looks to examine, through an analysis of the process of stigmatization, some of the beliefs that have been held in certain regions of sub-Saharan Africa with regards to individuals with albinism. The title of his research is; Albinism and the Contingencies of Stigma.

Jean Burke jeanburke76@gmail.com

A Ph.D graduate from Australia who lived in Tanzania for 12 years. She says: "I have started doing albinism research as I believe that it can make an important contribution to human rights responses."

Kelly Allen kllyalln@gmail.com Phone: (502) 553-4048 / <http://panamowa.blogspot.com/>

Kelly Allen is the author of "The Human Rights Case of Persons with Albinism in Uganda," (2011) from Fairfield University Press. She is a scholar on the socio-political status of persons with albinism around the world, with particular focus in Uganda and the Panama. She completed a Fulbright research grant on the positive associations of the condition of albinism amongst the Guna people of Panama in 2012. Currently, she serves as a resource to albinism organizations working to improve the social acceptance of PWA around the world.

Heather Werling hrwerlin@owu.edu

A Sociology and Black World Studies major at Ohio Wesleyan University.

Dr. Benson A. MULEMI and Mr. Urbunus M. NDOLO

bmulemi@yahoo.co.uk

I am an anthropologist from Kenya interested in ethnography of albinos and their livelihood in East Africa. My colleague and I are developing a research idea on this. (Department of Social sciences, Catholic university of Eastern Africa)

Mr. Muthee Thuku samthuku@yahoo.com

I am Mr. Muthee Thuku from Kenya. I am a trainer and researcher on monitoring, documenting and reporting on human rights violations and abuses in Africa with Amnesty International (Dutch Section) Special Programme on Africa (SPA). The title of my research project is; Myths, Discrimination and the Call for Special Rights for Persons with Albinism in Sub-Saharan Africa. The paper is now published online. To download the full paper, please follow the link below. <http://www.amanikenya.com/2011/04/the-kenya-bill-of-rights>

Caroline Ackley ceackley@gmail.com

I have recently concluded my masters' research from the University of Chicago on the killings of albinos in Tanzania. I would like to submit my research to Under the Same Sun in the hopes of helping. The title of her research project (attached) is; The Fetishization of Albinos in Tanzania.

Stacy Larson stacy_larson05@yahoo.com

I am a college professor but also a law student at Pace University School of Law in White Plains, NY. I have written a paper for my Refugee & Asylum Law class entitled, "Magic, Mutilation, and Murder: A Case for Granting Asylum to Tanzanian Nationals with Albinism." (attached). You can also access it online at:

<http://digitalcommons.pace.edu/cgi/viewcontent.cgi?article=1023&context=pilronline>

Lola Akinola Olatunji O.Olatunji@lboro.ac.uk

I was born in Nigeria and lived there till I was about 14 when I moved to the UK where I have been living for roughly 10 years. I am currently in the final year of my PhD at Loughborough University. I have a chemical engineering degree.

Lola has produced a 4 part documentary on albinism in Africa called: **History, Genetics, Myths & Health Care.**

Dr. Murray Brilliant BRILLIANT.MURRAY@mcrf.mfldclin.edu

Phone: 1-715-389-4976

A world renowned geneticist specializing in albinism. He recently completed a research project on PWA's in Tanzania. His trip was partially covered by Discovery Channel in an episode of "My Shocking Story: Albino Crisis".

Murray Brilliant, Ph.D.

Director, Center for Human Genetics

Marshfield Clinic Research Foundation

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WHRIN (Witchcraft and Human Rights Information Network).

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web: www.whrin.org

WHRIN is a UK based NGO that promotes awareness and understanding of human rights violations that are committed around the world due to the belief in witchcraft. WHRIN's values are:

- Grounded in the [Universal Declaration of Human Rights \(UDHR\)](#)
- Respectful of all faiths and cultures
- Based on a burning desire to fight injustice and speak up for the most vulnerable members of the global society.

In addition, there is a very significant non-academic resource you may want to consider:

Rick Guidotti

rick@positiveexposure.org Cell: 917-327-8485 <http://positiveexposure.org/>

A New York fashion photographer "gone rogue", Rick got tired of "being told" what beauty was and happened upon a PWA at a bus stop in NY city. This changed his life direction. He now goes all over the world capturing the beauty of persons with disability with a primary passion for albinism. He has helped set up "Albinism Societies" and support groups in many countries of the world, does awareness and fund raising via photo gala events, and has a particular passion for raising awareness about albinism with medical students early on in their training. Rick has also joined UTSS on several trips to Tanzania. He is a self-made expert on discrimination. His non-profit organization is called Positive Exposure. HE IS UNSTOPPABLE !!