



ROUNDTABLE DISCUSSION ON ACCESS TO HEALTHCARE AND EDUCATION FOR PERSONS WITH ALBINISM

Date: 12 November 2024

Venue: Hybrid (Face-to-Face: School of Financial Planning Law, University of the Free State, Bloemfontein Campus)

Organised by: Faculty of Law-Disability Rights Unit, Faculty of Health Sciences-Dermatology Department and Unit for Institutional Change and Social Justice

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BACKGROUND

Access to healthcare and education for persons with albinism are critical issues that impact their quality of life and well-being. Skin cancer risk, vision impairment, and discrimination are realities which need specialised medical care and support. The specialised healthcare services tailored to their specific needs, such as eye care, skin cancer prevention or psychosocial support, are often unavailable or very limited. Furthermore, discrimination, stigma, and the lack of knowledge about albinism create additional hindrances to seeking and accessing necessary healthcare services. Consequently, several persons with albinism are unable to enjoy their fundamental human right to healthcare.

Considering the advancements in health, measures to improve the availability, accessibility and quality of healthcare services for persons with albinism are necessary. In the same vein, education systems also need to approach albinism in a manner that addresses discrimination, stigmatisation, lack of reasonable accommodation, and inadequate support for learning. Many learners with albinism and their families face difficulties accessing education and even drop out.

In light of these realities, this one-day roundtable event seeks to bring together different experts to discuss access to healthcare and education by persons with albinism and ways to protect their healthcare and education rights. The focus contributes to reflections on the continued legal, policy and practical changes still needed to ensure the full and equal enjoyment of rights by persons with albinism. The date falls within disability rights awareness month.

PROGRAMME

12 November 2024

TIME	ACTIVITY
08:00 - 08:30	Registration
08:30 - 09:00	Welcoming – Prof Serges Djoyou Kamga (Dean of the Faculty of Law, UFS) & Prof Frans Maruma (Head of Department: Dermatology, Faculty of Health Sciences, UFS) Opening remarks – Dr Molapo Qhobela (Deputy Vice-Chancellor: Institutional Change, Strategic Partnerships and Societal Impact, UFS) Plan of the day – Dr Sandra Makwembere (WSU) & Ms Laetitia Fourie (UFS)
09:00 - 09:30	Opening Session
	Triumphs and Challenges of Persons with Albinism in South Africa 30 years after Democracy - Ms Nomasonto Mazibuko, Director of Albinism Society of South Africa
	The Role of the Commission for Gender Equality in Protecting the Rights of Persons with Disabilities - Commissioner Kamohelo Rodney Teele, Commission for Gender Equality
	The Role of the South Africa Human Rights Commission in Protecting the Rights of Persons with Disabilities – Commissioner Elspeth Nomahlubi Berlinda Khwinana, Commissioner of the South African Human Rights Commission
09:30 - 09:45	Interactive dialogue
09:45 – 10:00	Break
10:00 - 11:00	Session 1: Access to Health Care and Specialised Medical Care Beyond the Skin: Understanding Albinism's Medical, Socio- economic, Legal and Cultural Impact on Quality of Life - Prof Frans Maruma & Dr MH Makuru, UFS Access to Health Care and Specialised Medical Care for Persons with Albinism - Ms Siddeeqa Jhetam, UFS Equipping and Supporting the New Mother Through Strengthened Health Systems - Prof Ronell Leech, UP & Ms Meghann Buyco, Mothering and Albinism Project

PROGRAMME

TIME	ACTIVITY
	Impact of Climate Change on the Health of Persons with Albinism in Africa - Mr Andrews Kwame Daklo, Africa Albinism Network
11:00 – 11:30	Interactive dialogue
11:30 – 12:30	Session 2: Protecting the Rights of Persons with Albinism
	Protecting the Rights of Persons with Albinism - Prof Shari Parker, Global Albinism Alliance
	Legislative and Policy Framework for the Protection of the Rights of Persons with Albinism in Africa – Dr Dianah Msipa, Centre for Human Rights, UP
	An Overview of the Human Rights Situation of Persons with Albinism in South Africa – Ms Ntsikie Loteni, National Albinism Task Force of South Africa
	Advancing Educational Equity for Persons with Albinism: A Rights-Based Approach to Safeguarding Access and Inclusion in Line with International Human Rights Standards - Prof Lizelle Ramaccio Calvino, UNIZULU
12:30 – 13:00	Interactive dialogue
13:00 – 14:00	Lunch
14:00 – 14:30	Virtual Exhibition
	"Art as a form of Activism" by Ms Athenkosi Kwinana, Berman Contemporary
	"Self-Portraits" by Mr Zamo Ndhlazi
14:30 – 14:45	Interactive dialogue
14:45 – 15:00	Session 3: Psycho-Social support and Combating Stigma
	Psycho-Social Support and Combating Stigma – Ms Daphney Poppy Neke-Smith, Albinism Society of South Africa

PROGRAMME

TIME	ACTIVITY
15:00 – 15:15	Interactive dialogue
15:15 – 15:50	Session 4: Inclusive Education
	Changing Minds and Changing Lives through true Disability inclusion - Mr Zingisile Sesing, UFS CUADS
	My Personal Experience Living with Albinism - Ms Precious Tirivanhu, UFS postgraduate student and researcher
	Let In or Let Out – Ms Pila-Sande Mkuzo & Ms Tshegofatso Phala, Equal Education Law Centre
15:50 – 16:00	Interactive dialogue
16:00 – 16:30	Way Forward
	Global Conference on Albinism
	Book Project
	UFS Vision 130 - Prof Tameshnie Deane, Vice-Dean: Research and Postgraduate Studies, Faculty of Law, UFS
	Word of Thanks – Prof Serges Djoyou Kamga, Dean of the Faculty of Law, UFS
16:30	Close (Venue to be vacated)

PRESENTERS

PROF SD KAMGA DEAN OF THE FACULTY OF LAW, UNIVERSITY OF THE FREE STATE



Professor Serges Djoyou Kamga is a full Professor of Human Rights Law and the Dean of the Faculty of Law at the University of the Free State, South Africa. He is currently the Vice President of the ANCL (Central Africa Region). He is also a member of the Executive Committee of the International Association of Constitutional Lawyers. Prof Kamga previously worked at the Thabo Mbeki African School of Public and International Affairs (UNISA), the Centre for Human Rights (University of Pretoria) and at the South African Institute for Advanced Constitutional Law (SAIFAC), a Centre of the University of Johannesburg. his research over the years demonstrates a profound and sustained commitment to advancing knowledge about human rights in Africa, especially on the right to development in the African human rights system, human rights from cross-cultural perspectives and disability rights.

His research also includes illicit financial flows and their impact on human rights in Africa. He is the author/editor/co-editor of 10 books and 70 articles/book chapters. Prof Kamga has received several research grants and awards, including the prestigious Ali Mazrui Award for Scholarship and Research Excellence for 2021.

PROF F MARUMA HEAD OF DEPARTMENT: DERMATOLOGY, UNIVERSITY OF THE FREE STATE



Professor Frans Maruma (MBChB, DipHivMed, DipAesthMed, Mmed, FCDerm, PhD) is a renowned dermatologist with a deep interest in the diagnosis and treatment of rare dermatological diseases. Amongst other credentials, he holds both Masters and Doctoral degrees in dermatology (PhD) from the University of the Free State, where his expertise spans a wide range of areas, including aesthetic medicine, cosmetic dermatology, and dermatopathology. Prof Maruma is especially recognised for his research on Oculocutaneous albinism, leprology, hidradenitis suppurativa and chronic pigmentary disorders in Fitzpatrick skin types IV–VI (Darker skin type), with his findings frequently presented at international congresses and published in leading scientific journals.

In addition to his clinical work, Prof Maruma is a passionate educator, teaching both undergraduate and postgraduate students in the School of Clinical Medicine, University of the Free State, while advancing research in cutaneous medicine. He holds key roles such as ambassador for Golden Key International Society, member of various advisory boards on pharmaceuticals, Honorary Secretary of the College of Dermatologists of South Africa and serves on the Council for the KwaZulu-Natal College of Emergency Care, to name a few. Furthermore, he contributes as an Associate Editor for the International Journal of Women's Dermatology and serves as a scientific reviewer for prominent international journals.

Highly regarded in the field of mental well-being and aesthetic medicine, Prof Maruma is a motivational speaker, and he is also an expert in neurotoxins (BTA) and hyaluronic acid (HA) filler treatments, regularly training professionals in advanced dermatologic procedures. Outside of his career, he enjoys spending time with family, travelling, and listening to music.

DR M QHOBELA

DEPUTY VICE-CHANCELLOR: INSTITUTIONAL CHANGE, STRATEGIC PARTNERSHIPS AND SOCIETAL IMPACT, UNIVERSITY OF THE FREE STATE



Dr Molapo Qhobela is a seasoned leader in education, science and technology, with over 30 years of professional experience. Dr Qhobela holds a BSc from the University of Zimbabwe and a PhD from Kansas State University in the United States. With a doctorate in Plant Pathology, Dr Qhobela has served as the Chairperson of the Board of the South African Agricultural Research Council and a board member of the International Crops Research Institute for the Semi-Arid Tropics (ICRISAT). Dr Qhobela is currently the Chairperson of TENET, and previously served as the Chairperson of the Global Research Council (GRC) and on the Boards of the South African Qualifications Authority (SAQA), the Council on Higher Education (CHE), and the National Advisory Council for Innovation (NACI).

Dr Qhobela has dedicated his professional career to the development and transformation of the South African higher education, science, technology and innovation system. He has held academic positions at Rhodes University and the University of Cape Town; executive leadership roles at the University of South Africa; and senior management positions in the South African Departments of Education and Science and Technology. Dr Qhobela is currently the Deputy Vice Chancellor for Institutional Change, Strategic Partnerships and Societal Impact at the University of the Free State, and the immediate past Chief Executive Officer of the South African National Research Foundation.

DR S MAKWEMBERE

WALTER SISULU UNIVERSITY



Sandra Makwembere is a Senior Lecturer at Walter Sisulu University. She holds a PhD in Industrial and Economic Sociology and Postgraduate Diplomas in Education and Disability Studies. Before her academic career, she spent six years working in the non-profit sector on social accountability projects across Southern Africa which enhanced her expertise in public resource management and social justice.

Her research focus areas include disability inclusion, technological change and public policy. Her current research focuses on disability-inclusive education and work environments.

MS L FOURIE UNIVERSITY OF THE FREE STATE



Laetitia Fourie is the Programme Director of the Centre for Labour Law at the University of the Free State where she manages short learning programmes in Labour and Commercial law. She is a lecturer in the Department of Mercantile law, where she teaches Labour Law, Credit Law and Consumer Protection.

She holds an LLB degree (Cum Laude) and LLM degree in Mercantile Law (specialisation in Labour Law). She is an admitted Attorney of the Free State High Court. Laetitia also holds a Postgraduate Diploma in Financial Planning and passed the CFP board examination.

Laetitia conducts research in Labour and Disability Law and has delivered international and national papers on these topics. She is currently a PhD candidate at the University of Leiden, conducting research on the protection of employees with disabilities. She is passionate about the protection of the rights of those with disabilities. Her most recent research relates to the protection of persons with albinism.

MS N MAZIBUKO

DIRECTOR: ALBINISM SOCIETY OF SOUTH AFRICA



Nomasonto Mazibuko, an educator, has worked for the Department of Education for a period that spans over three decades. She devoted her life to fiercely advocating for persons with albinism in South Africa and throughout the African continent. Inspired by the spirit of Africanism, she founded the Albinism Society of South Africa (ASSA) and the Pan African Albinism Alliance (PAAA).

Her advocacy has ensured the recognition of persons with albinism by the United Nations by declaring June 13 as International Albinism Day. Her passion for disability rights resulted in being appointed a member of the Presidential Working Committee, the National Disability Policy review panel as well as several boards and initiatives in support of social justice. Examples of these structures are:

- The Panel of Arbitrators for Non-Profit Organisation undersigned to the Department of Social Development where she acts as Chairperson;
- The Department of Arts and Culture where she is a Social Cohesion Advocate;
- The Section 11 Committee on Children's Rights and Rights of persons with disability for the South African Human Rights Commission; and
- The Platform of Champions where Nomasonto leverages and amplifies the work undertaken, to achieve United Nations Sustainable Development Goal 8.5 on equal pay for work of equal value between men and women globally.

Nomasonto Mazibuko acquired a range of qualifications enabling her to respond competently to the demands of her journey thus far. These include Primary Education Teachers Diploma (Eshowe Teachers Training); Conflict Resolution Diploma (Vista -UJ); Project Management (Wits); and Advance Educational Training (UCLA).

COMMISSIONER KR TEELE

COMMISSIONER: COMMISSION FOR GENDER EQUALITY



Kamohelo Rodney Teele holds a Bachelor of Education Honours from the University of Witwatersrand. He has extensive experience in Disability Non-Governmental Organizations advocating for the rights of persons with disabilities. He possesses sound knowledge, skill and advocacy in Inclusive and Special Needs Education, policy development and framework in disability rights, local government, strategic leadership, and communications.

He was appointed by the Head of State His Excellency President Cyril Ramaphosa in terms of Section 193(4)(b) of the constitution to become Commissioner of Commission for Gender Equality effective from October 2024 to 2029.

COMMISSIONER ENB KHWINANA

FULL-TIME COMMISSIONER: SOUTH AFRICAN HUMAN RIGHTS COMMISSION



Elspeth Nomahlubi Berlinda Khwinana is a renowned admitted attorney and a respected figure in the legal field, with an extensive career spanning over two decades. She holds an LLB and BJURIS degree from the University of North West and has been the Director of Mtimkulu Khwinana Attorneys since 2001. Elspeth's legal prowess encompasses various domains, including civil litigation, family law, and criminal law, showcasing her diverse expertise.

Since 2020, Ms Khwinana has served as an acting Judge of the Gauteng High Court, significantly contributing to jurisprudence through her insightful judgments. Her role extends beyond the courtroom; she is a fervent activist for Gender-Based Violence and Femicide (GBVF) and a staunch feminist. As the National Coordinator for the South African Women Lawyers Association (SAWLA) Student Chapter, she is committed to empowering the next generation of attorneys, particularly women. Her efforts in mentoring aspiring lawyers highlight her dedication to nurturing talent and promoting gender equality in the legal profession.

Ms. Khwinana's influence transcends her professional obligations. She is a community leader who actively shares her knowledge and experience in churches and surrounding communities, emphasizing the importance of legal awareness and advocacy. Her role in organizations like SAWLA, National Democratic Lawyers Association (NADEL), and Lady of Peace Community Foundation (LOPECO) further exemplifies her commitment to legal excellence, peace, and community service. Ms. Khwinana is not just a legal professional; she is a beacon of hope and empowerment, shaping the legal landscape while inspiring and uplifting those around her.

Ms Khwinana has distinguished herself as a dedicated human rights activist, fervently working towards the advancement of fundamental rights and freedoms. Her activism is characterized by a deep commitment to addressing and resolving human rights violations, with a particular focus on the rights of the underrepresented and marginalized.

She is known for her tireless efforts in advocating for justice and equality, utilizing her legal expertise to challenge injustices and champion the cause of those without a voice. Her endeavours in this field are not just confined to legal battles; they also encompass educational outreach, where she enlightens and engages communities on their rights, fostering a culture of awareness and empowerment.

DR MH MAKURU UNIVERSITY OF THE FREE STATE



Dr MH Makuru is a prominent specialist dermatologist based in Bloemfontein, South Africa. She has made significant strides in the field of dermatology over the past few years. She completed her medical degree at the University of Free State, where she excelled in her studies and developed a keen interest in dermatology. Following her medical training, Dr Makuru pursued specialised training in dermatology at the University of the Free State, where she honed diagnostic and treatment skills. With her strong academic background and specialised training, her passion for patient care and commitment to staying abreast of the latest advancements in dermatological research and technology have set her apart as a trusted and respected healthcare provider in her community. One of Dr Makuru's notable professional accomplishments is the involvement in research and publication of a few articles. Dr Makuru is actively involved in teaching and mentoring medical students and residents at the University of Free State's Department of Dermatology.

As a dedicated educator, Dr Makuru is passionate about sharing her knowledge and experience with the next generation of dermatologists, helping to shape the future of dermatological care in South Africa. Her commitment to education and mentorship has been instrumental in inspiring aspiring dermatologists and fostering a culture of excellence in dermatology training programs. She acts as a head of Department at the University of the Free State, with strong administrative and management skills. She has done presentations across the country, and a few presentations internationally. Outside normal hours, she also practices in private practice, and she is also involved in clinical trials as a sub-investigator.

MS S JHETAM UNIVERSITY OF THE FREE STATE



Siddeeqa Jhetam is an optometrist with experience in the private, public and academic sectors. At the University of the Free State, she holds the role of a published lecturer, undergraduate and postgraduate research supervisor and is an active member of the Health Sciences Research Ethics Committee. Her areas of focus are low vision rehabilitation and dispensing optics. Her Masters degree at the University of KwaZulu-Natal centred around oculocutaneous albinism and telescopes and she has served as a peer reviewer and examiner of related postgraduate projects.

Her role as a supervising optometrist at the low vision patient clinic at Universitas Annex Hospital involves the management of persons with visual impairments, including albinism and she is regularly consulted by the Free State Society for the Blind.

MS M BUYCO MOTHERING & ALBINISM PROJECT



Meghann Buyco MSN RN is a nurse in Canada who specializes in providing care for older adults as well as patients undergoing cancer treatments. She is currently a PhD in nursing student at Trinity Western University, Canada. She is the Project Coordinator of an international research-policy-advocacy network, Mothering & Albinism, supporting research on mothering, albinism and human rights in South Africa, Tanzania, Ghana and Canada. Meghann dedicated her master's in nursing thesis to the experiences of siblings impacted by albinism in Africa. She is passionate about disability and human rights, and ensuring the protection and promotion of the rights of persons with albinism and their families.

PROF R LEECH

UNIVERSITY OF PRETORIA



Prof Ronell Leech is an Associate Professor in the Department of Nursing Science at the University of Pretoria, specialising in nursing leadership. She has supervised several postgraduate students in leadership-focused research. With a master's in early childhood intervention, she has a strong interest in the health of vulnerable populations. Currently, she is engaged in a project exploring human rights and equity-oriented responses to the birth experiences of families affected by albinism in Sub-Saharan Africa, conducted in collaboration with Trinity Western University in Canada.

MR AK DAKLO AFRICA ALBINISM NETWORK



Andrews Kwame Daklo is a disability rights advocate from Ghana with experience in human rights advocacy, focusing on albinism, programming and social work. Kwame holds a Masters degree in Human Rights and Democratisation in Africa from the Centre for Human Rights, Faculty of Law, University of Pretoria.

Kwame has a vast experience in community mobilisation, program facilitation and social media advocacy on the rights of persons with albinism. He is passionate about promoting and protecting the rights and welfare of persons with albinism in Ghana and Africa.

PROF S PARKER

GLOBAL ALBINISM ALLIANCE



Professor Shari Parker is a specialist physician, educator and albinism advocate and is legally blind from oculocutaneous albinism

Shari graduated from Medicine with honours and completed a Masters in pain management and Fellowship in Rehabilitation Medicine, being awarded the prize for the best performance in the fellowship clinical examination in Australasia. She's acknowledged as "one of the most accomplished and respected Rehabilitation Doctors in Australia".

She's passionate about medical education, completed a Masters of Education and has served as the coordinator of education and chief examiner for Rehabilitation Medicine in Australasia.

Shari was a founder and inaugural president of the forerunner to the Global Albinism Alliance and has been acknowledged as a champion for the albinism cause, speaking at an expert meeting at the UN which was a prelude to the appointment of the UN's independent expert on albinism.

Shari is a mother of three teens and in her spare time enjoys Rubik's cubing and playing the flute.

DR D MSIPACENTRE FOR HUMAN RIGHTS, UNIVERSITY OF PRETORIA



Dr Dianah Msipa is an experienced human rights researcher and programme manager with expertise in International Human Rights Law, particularly Disability Rights Law and Policy, and 15 years' work experience. She holds a Doctor of Laws (LL.D) degree from the University of Pretoria in South Africa, a Master of Laws (LL.M) degree from McGill University in Canada, a Post-graduate Diploma in Legal Practice (LPC) from Northumbria University in the United Kingdom, and a Bachelor of Laws degree (LL.B Hons) from Newcastle University in the United Kingdom.

She is an author with numerous publications in peer reviewed journals and books including Springer; Psychology, Law and Public Policy; Drexel Law Review; the South African Journal on Human Rights and the African Disability Rights Yearbook.

MS N LOTENI NATIONAL ALBINISM TASK FORCE OF SOUTH AFRICA



Ntsikie Loteni holds an Honours degree in Industrial Psychology from Fort Hare University and a Masters in Management from Wits. Her career began in 2005 as a Human Resources Intern at the National Treasury until she became Deputy Director of Talent Management in 2012. Later, she joined the Department of Trade, Industry and Competition and Johannesburg Water, respectively, where she addressed inequality, unfair discrimination, and institutional culture issues.

In September 2020, she accepted a Director: Transformation role at the University of Pretoria. In this role, she drives the University's transformation goal of being a transformed, equitable and inclusive institution.

Ms Loteni plays a significant role in civil society work. She is a member of the National Albinism Task Force of South Africa, advocating for the rights of persons with albinism. She is also a founder of Ibutholezwe Foundation, a non-profit organisation that drives work on access to inclusive education and employment of persons with albinism.

PROF LR CALVINO UNIVERSITY OF ZULULAND



Professor Lizelle Ramaccio Calvino (B.Proc (UP) MBA (USQ Aus) LLM *cum laude* (UNISA) LLD (UNIZULU) PGDipHE *cum laude* (UKZN)) is an Associate Professor of Private Law at the University of Zululand and serves as Acting Director of Judicial Services.

Admitted as an attorney in 1999, Prof Calvino has extensive legal and academic experience, particularly in family law, child law, and constitutional law. In addition to her academic role, she served as a member of the University Council and actively contributes to UNIZULU's institutional committees. She is widely published, with contributions in both national and international journals and book chapters and has supervised numerous postgraduate students. Her commitment to community engagement resulted in her being awarded the Vice-Chancellor's Award for Community Engagement in 2022.

She also serves as an NRF reviewer as well as a reviewer of SAPSE-accredited journals. Her research interests focus on legal pedagogy, matrimonial law, human rights and constitutional law. Prof Calvino is also a regular presenter at conferences, sharing insights on education, law, and the integration of technology in legal education.

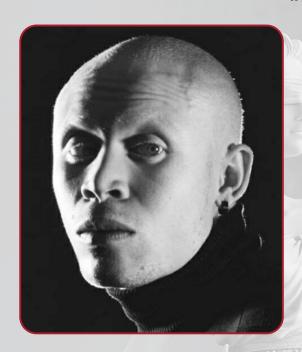
MS A KWINANA ARTIST: BERMAN CONTEMPORARY



Athenkosi Kwinana (b. 1995) is a Johannesburg-based visual art activist specialising in drawing and printmaking. She earned her National Diploma and Bachelor of Technology in Fine Arts from Walter Sisulu University, followed by a Master's from the University of Johannesburg in 2022. Kwinana held her first solo exhibition, "REIMAGINING ALBUS," that year and began her "DISPLACEMENT IN COMMUNITY: THE COLOUR SERIES" during an artist residency in Muizenberg. In 2022, she received the Cultures Resistance Award and participated in multiple group exhibitions, including the 1-54 Contemporary African Art Fair in London.

In 2023, she continued to showcase her work internationally, completing a residency in Cuba and receiving grants for her art. In 2024, she featured at the 1-54 Contemporary African Art Fair in New York and opened her second solo exhibition, "Ndijongile," while also engaging in various discussions on inclusivity and albinism awareness.

MR Z NDHLAZI INDEPENDENT ARTIST



Zamo Ndhlazi is a Pretoria-based photographer and filmmaker. His photography career began in the year 2016 when he enrolled at the Tshwane University of Technology. He currently holds a B-Tech in photography obtained in the year 2019.

His approach to photography is more of storytelling and this can be included in all genres of photography. He is well-trained in all genres, and he does his best not to limit himself to one specific genre. In most cases, he lets the audience decide on which genre suits him the best. He enjoys documentary photography because of his love for traveling and this gives him the energy and drive to capture the daily surroundings of this world.

Artistically, he takes time to create self-portraits, and he believes this will be his signature trademark. He says this because if someone does not know him personally, he/she will know the type of person that he is through his self-portraits.

His experience in photography throughout theses years has been enormous but there were a lot of obstacles throughout the journey. He has worked on campaigns such as the Ebola campaign with the South African legendary singer Yvonne Chaka-Chaka. Other big campaigns include BRIKS, McDonald's, SANRAL seminars and workshops. He won an award at the Artfluence Photography Competition obtained in the year 2023.

ARTISTIC STATEMENT

My approach to photography tells many stories in a human's head. I know the story behind every image that I capture, but I let the audience decide the meaning behind the image in their own point of view. For the incubation programme, my focus is capturing all aspects of portraiture across different generations from child portraits to elderly portraits. The goal is to produce a body of work using different lighting techniques both in studio and location.

MS DP NEKE-SMITH ALBINISM SOCIETY OF SOUTH AFRICA



Daphney Poppy Neke-Smith is a person with Albinism working in the Developmental Communications space. She was born and bred in Sebokeng, in the Vaal Triangle. Poppy is also a mom to two children with albinism. After graduating from Wits University, she spent 18 months volunteering at the Albinism Society of South Africa (1999 to 2000). During this time, she learnt invaluable skills and came to understand the critical role played by social support networks such as support groups for mothers and families raising children with albinism.

Poppy has previously served as a board member of the Albinism Society for over 10 years. She holds a BA Education Honours Degree and a Post-Graduate Diploma in Media Studies and Journalism from the University of the Witwatersrand. She is one of the recipients of the 2013 Tributes Awards for Women with Disabilities.

MR Z SESING

CENTER FOR UNIVERSAL ACCESS AND DISABILITY SUPPORT, UNIVERSITY OF THE FREE STATE



Zingisile Sesing was born in the Free State, and completed his matric at Bartimea school in Thaba Nchu. Thereafter he came to the University of the Free State to complete a BA general degree majoring with political science and History.

Thereafter he started his career at Motheo TVET College where he working as a Braillist. Currently, he is working at the University of the Free State under the division of Student Affairs in the Center for Universal Access and Disability Support (CUADS) as a disability officer.

MS SP TIRIVANHU UNIVERSITY OF THE FREE STATE



Shamiso Precious Tirivanhu holds an LLB degree and is an LLM candidate.

She works as a research assistant in the Mercantile Law department of the Law Faculty at the University of the Free State.

MS PS MKUZO EQUAL EDUCATION LAW CENTRE



Pila-sande Mkuzo is from East London in the Eastern Cape. She completed her Bachelor of Laws degree at the University of Fort Hare in 2017. She was awarded the Canon Collins Leigh-Day Scholarship and in 2018 received the Dean of Research Exceptional Achievement Award.

Pila-sande has been active in social justice work, including forming part of the steering committee of the East London #TheTotalShutdown and the HIV Policy Conference. She is currently the chairperson of Passionate Unlimited Peers in Action (PUPA) an NGO based in the Eastern Cape. She has also served under the Eastern Cape Aids Council Women's Sector and the NACOSA Provincial Advisory Committee.

Pila-sande joined the Equal Education Law Centre ("EELC") in 2019 as Candidate Attorney and Bertha Justice Fellow. She was later admitted as an Attorney in late 2020 and has been practicing as a public interest attorney since. Her areas of expertise include Disciplinary Procedures in School, Regulation of Private Actors, Rights of LGBTQI persons, Infrastructure and Community Engagement.

MS T PHALA EQUAL EDUCATION LAW CENTRE



Tshegofatso "Tshego" Phala is an accomplished public interest lawyer with over 15 years' experience in public interest litigation. Holding a Bachelor of Arts and LLB degree from the University of Witwatersrand, Tshego practiced as an attorney in the Pro Bono Department at Webber Wentzel Attorneys between 2011 and 2016 and was appointed as a partner in 2017.

Keen to embed herself in movement lawyering, she joined the Initiative for Strategic Litigation in Africa (ISLA) in February 2019 leading their Sexual Rights Litigation in Africa. She is also a 2020/21 Fellow of the Mandela Washington Fellowship for young African leaders and was the Chairperson of the board of the National Council of and for Persons with Disabilities in South Africa.

In the course of her practice, Tshego was part of a number of landmark cases that advanced the rule of law and constitutional democracy in South Africa, as well as the protection and advancement of the rights of LGBTQI persons (with particular focus on LGBTQI youth, transgender and intersex persons).

Tshego has a passion for human rights and the protection of vulnerable and marginalized persons and communities in society. She believes that movement-led lawyering and community lawyering can contribute positively to bringing about social change and the legal empowerment of marginalized voices.

Tshego is currently the Executive Director of Equal Education Law Centre (EELC), a public interest law clinic working to further the struggle for education justice and redress in South Africa through legal activism. She believes that education and its advancement is a crucial catalyst for social change.

PROF T DEANE VICE-DEAN: RESEARCH AND POSTGRADUATE STUDIES, FACULTY OF LAW, UFS



Professor Tameshnie Deane is an NRF-rated Law Professor with over 23 years of experience in academia. In addition to her contributions to the teaching and learning environment, she has published widely in accredited journals, spoken at several national and international conferences and been recognised through various awards. In pursuance of engaged scholarship initiatives, she sits as chair and a member of different committees, boards and non-profit organisations.

Prof Deane is an admitted Advocate and since 2019 she sits on occasion, as an Acting Judge in various divisions of the High Court of South Africa. Most recently she has been appointed as an Acting Judge of the Limpopo Division of the High Court. As an academic, advocate and part-time member of the judiciary, she finds herself in a unique position to pursue, amongst other goals, advocacy initiatives, social justice and reform, access to justice and constitutional transformation initiatives from different platforms.

