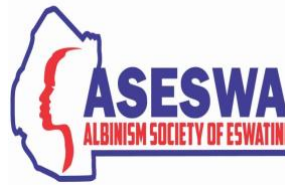




Africa Albinism Alliance



## Submission to the Committee on the Rights of the Child on the situation of children with albinism in Eswatini

Submission by **Africa Albinism Alliance, Albinism Society of Eswatini and Swaziland Association of Persons with Albinism** to the Committee on the Rights of the Child on the situation of children with albinism in Eswatini.

*18 August 2021*

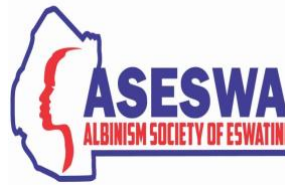
### **Submitting organisations:**

The Africa Albinism Alliance, Albinism Society of Eswatini and Swaziland Association of Persons with Albinism welcome the opportunity to jointly submit this report for consideration during the Committee on the Rights of the Child (CRC Committee) state review of Eswatini.

- **Africa Albinism Alliance**, established in February 2021 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 in Africa. The Alliance aims to ensure that the [African Union Plan of Action to End Attacks and other Human Rights Violations Targeting Persons with Albinism \(2021-2031\)](#) is implemented at the national level, including through national action plans with multi-year budgets; and that the positive effects of these measures concretely advance the enjoyment of human rights by persons with albinism in the Africa region.
- **Swaziland Association of Persons with Albinism (SAPA)** was founded in 2013 by Philemon Gama and registered in 2016. It is the first Swati Association to raise awareness on the conditions of persons with albinism (PWA) in Eswatini.



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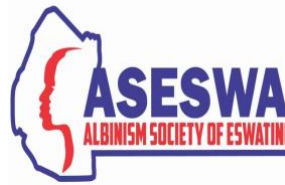
- **Albinism Society of Eswatini's** vision is to enhance awareness on albinism in Eswatini by educating and providing user friendly information on albinism to communities and dispelling myths and misconceptions about albinism.

**Contact:**

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This submission centers on ongoing issues and challenges experienced by children with albinism, one of the less visible groups of children with disabilities in Eswatini (formerly Swaziland) in accessing their human rights. It is based on the contributing organization's firsthand information and experience; published research on the issue, credible media reports as well as information derived from the reports of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. The submission specifically highlights the government of Eswatini's failure to ensure the rights to inclusive education, adequate standard of health, personal security, benefit from social security and right to life of children with albinism in the country.

### **The human rights situation of children with albinism in Eswatini**

Albinism is a relatively rare, non-contagious, genetically inherited condition in which a person produces little to no melanin, resulting in little to no pigmentation, in the skin, hair, and eyes. This lack of melanin often results in a pale or "white" appearance compared to other members of their family, community, or ethnic group causing hypervisibility. In addition, the lack of melanin results in two congenital and permanent health conditions: visual impairment of varying degrees as well as high vulnerability to skin damage from ultraviolet rays, including skin cancer. Albinism affects people worldwide regardless of race, ethnicity, or gender.<sup>1</sup>

In Africa, estimates on the occurrence of albinism range from 1 in every 5,000 people to 1 in every 15,000. In some populations in the region, including in Southern Africa, where Eswatini is located, it may be as high as 1 in 1,000.<sup>2</sup> Up-to-date reliable statistics on the number of persons with albinism remains a challenge on the continent. The Population

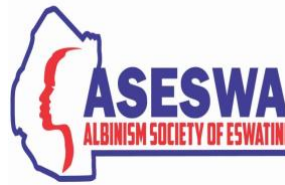
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<sup>1</sup> Report of the Independent Expert on the enjoyment of human rights by persons with albinism Worldwide A/74/190.

<sup>2</sup> Preliminary Report of the United Nations High Commissioner for Human Rights, "Persons with Albinism," September 12, 2013 at para 14, [http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A\\_HRC\\_24\\_57\\_EN\\_G.doc](http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_EN_G.doc), and Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, "Albinism in Africa as public health issue", BMC Public Health, vol. 6, No. 212 (August 2006). [www.biomedcentral.com/1471-2458/6/212](http://www.biomedcentral.com/1471-2458/6/212)



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and housing census of 2017 puts the total number of persons with albinism at 7 332 with 4191 of these being children.<sup>3</sup> These figures are disputed by organisation working on albinism in Eswatini who believe that the figures are higher. They attribute the low estimates partly to families hiding members with albinism during such surveys particularly children.

### **Compliance with the provisions of the on the UN Convention on the Rights of the Child**

#### **Articles 6 & 37 Right to life and freedom from torture or cruel, inhuman or degrading treatment or punishment of children**

There have been twelve recorded attacks against persons with albinism for ritual purposes in Eswatini since 2010, four of which were murders.<sup>4</sup> The following attacks recorded involved child victims:

- In 2010 two children were murdered in the Shiselweni region. The two victims were pupils attending primary school. They were attacked while running family errands after school. The perpetrators of these attacks were never apprehended.<sup>5</sup>
- The first victim, a teenage with albinism was found murdered and mutilated.<sup>6</sup>
- The second victim, Banele Nxumalo, an eleven-year-old girl with albinism, was fatally shot and beheaded by masked men at a river at Sigudvuma whilst collecting water. Her decapitated body was discovered a few days after the attack a short distance away from the scene of the attack.<sup>7</sup>

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<sup>3</sup> Swaziland Population and Housing Census 2017  
(<http://ghdx.healthdata.org/organizations/central-statistical-office-swaziland>)

<sup>4</sup> <https://actiononalbinism.org/page/vgopnjrnzvs;>  
<https://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf>

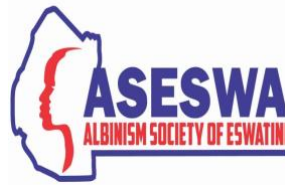
<sup>5</sup> Permanent Mission of the Kingdom of Swaziland; Chemin William Barbey 51-1292 Chambsey-Switzerland; Note verbal No 191/2014  
(<https://www.ohchr.org/Documents/HRBodies/HRCouncil/AdvisoryCom/Albinism/Swaziland.pdf>)

<sup>6</sup> Ibid.

<sup>7</sup> Ikponwosa Ero, United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, foreword to the International Bar Association report, 'Waiting to disappear' International and Regional Standards for the Protection and Promotion of the Human Rights of Persons with Albinism June 2017; The Swazi Observer-Albino girl shot mutilated



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- In 2018 a traditional healer (inyanga) from Eswatini was implicated in the kidnapping and murder of two children in South Africa Nkosikhona Ngwenya and Gabisile Shabani who had albinism. He was arrested after police found a human head and other human body parts at his home.<sup>8</sup>

The full extent of violent crimes targeting children with albinism in Eswatini is unknown, as most attacks against persons with albinism are believed to go unreported for various reasons, including the involvement of family members, a culture of silence around such crimes as well as a lack of formal monitoring mechanisms to accurately track and report cases. These attacks are often driven by erroneous beliefs that the body parts of persons with albinism when used in witchcraft rituals can bring riches, success, power or sexual conquest. The body parts of children are considered even more potent because of their innocence. These myths and the resulting attacks are often perpetuated and fuelled by unscrupulous traditional healers.<sup>9</sup>

Children with albinism are at a heightened risk of being attacked, their safety security is thus an issue of grave concern that needs to be addressed. According to a report by the Stukie Motsa Foundation in March 2018, three families with children with albinism reported to the police that they were approached by unknown people to give them their children in exchange for money.<sup>10</sup> On November 25, 2019, a 3-year-old girl with albinism

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(<https://actiononalbinism.org/api/files/1532561120559tyy037k8xn35f87raindhd7vi.pdf>); IOL-Albino girl grabbed by masked man (<https://www.iol.co.za/amp/news/africa/albino-girl-grabbed-by-masked-man-673886>)

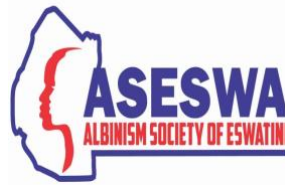
<sup>8</sup> <http://www.times.co.sz/news/117228-swazi-inyanga-in-murder-of-two-children-revealed.html>

<sup>9</sup> In May of 2016 in Nkoyoyo, Swaziland, a man with albinism by the name of Sipho Mahlalela was murdered by his wife, Pinky Zikalala. She hired 2 men to kill her husband and then tried to sell his corpse to a traditional healer (name withheld) who allegedly entered into an agreement with her. He is now the subject of intense police investigation. The wife along with the two men have since been arrested and charged for the murder. Prior to their arrest, Pinky Zikalala took the traditional healer to see the corpse at which time she asked to be paid for keeping her end of the agreement. The traditional healer is said to have backed out of the deal because he wanted Mahlalela to be brought to him alive since he needed the blood of a person with albinism for ritual purposes. (Source: TIMES OF SWAZILAND; WIFE ACCUSED OF SELLING ALBINO'S CORPSE TO INYANGA; May 27, 2016; BY THEMBINKOSI MAVIMBELA; <http://www.times.co.sz/news/108061-wife-accused-of-selling-albino%E2%80%99scorpse-to-inyanga.html>)

<sup>10</sup> <https://stukiefoundation.org/about-us/>



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and her mother narrowly escaped a dangerous encounter in the Southern part of the Lubombo region in Eswatini after unknown men arrived at their home demanding the child with albinism. Fortunately, the mother and child were not home at the time. The matter was reported to the police and the mother and child went into hiding.<sup>11</sup>

The media's reporting on the attacks has inadvertently put a price tag on children with albinism and also made children with albinism fearful that they may be attacked for their body parts. Some parents and communities of children with albinism have become hyper vigilant restricting children with albinism from freely playing outside.

The recent Covid 19 pandemic has multiplied this risk. Organisation working on albinism have expressed concern that children with albinism are at increased risk of attacks for their body parts during the lockdowns implemented by government to curb the spread of the virus because they are potentially locked down in insecure homes and communities with suspected perpetrators.<sup>12</sup>

The Government of Eswatini has condemned the attacks against persons with albinism on several occasions. In 2010, the Police in the country, set up a national register for persons with albinism. It was intended to keep track of all Eswatini residents with albinism to deter ritual attacks. However, it is not clear if the register is still active.<sup>13</sup>

## Article 2 Prohibition against discrimination on the basis of colour

The United States Department of State reported in 2013 that persons with albinism in Eswatini are stigmatised and discriminated against. The department reported that this

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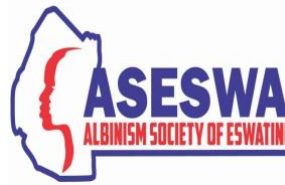
<sup>11</sup> On February 2, 2020, Philemon Gama, President of Swaziland Association of Persons with Albinism – SAPA, issued a Facetime report of the incident to IK Ero, Independent Expert of the Enjoyment of Human Rights by Persons with Albinism.

<sup>12</sup> <https://stukiefoundation.org/about-us/>

<sup>13</sup> <https://actiononalbinism.org/page/vgopnjrnzvs>



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discrimination was still present in 2016.<sup>14</sup> Stigma towards persons with albinism is widespread due to ignorance and myths associated with the condition. Some communities in Eswatini believe that persons with albinism are “ghosts” or have magical powers; that they are the result of incest or a curse. Children with albinism face discrimination based on the colour of their skin but because they are a minority and marginalized group in society, discrimination against them is simply overlooked and unreported.

## Article 24: Right of the child to the enjoyment of the highest attainable standard of health

### *Skin cancer prevention and treatment:*

Children with albinism in Eswatini are at high risk of ultraviolet induced skin damage due to the lack of melanin in their skin and the fact that this age group has more time and opportunity to be outdoors in the sun. They are highly susceptible to developing skin lesions that have both cosmetic and health complications, with a high risk of developing skin cancer in later years.<sup>15</sup> Skin cancer is a primary cause of early death in most persons with albinism in Africa. The United Nations posits that most persons with albinism do not live past the age of 40 due to skin cancer related illnesses.<sup>16</sup> In Eswatini, there are no official statistics about skin cancer-related deaths among persons with albinism, but research in similarly situated countries shows that harsh climatic conditions coupled with poor sun protective behaviour increases skin cancer risks among this group.<sup>17</sup> The correct and consistent application of good quality sunscreen reduces the vulnerability of persons with albinism to the effects of the ultraviolet radiation (UVR) from sunlight.

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<sup>14</sup> Ibid.

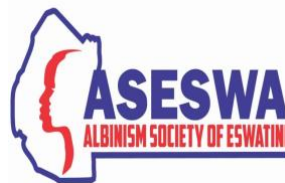
<sup>15</sup> Lack of adequate sun protection for children with oculocutaneous albinism in South Africa <https://bmcpublikealth.biomedcentral.com/articles/10.1186/1471-2458-8-225>.

<sup>16</sup> Report by I. Ero, independent expert for the United Nations, 2015.

<sup>17</sup> Lack of adequate sun protection for children with oculocutaneous albinism in South Africa <https://bmcpublikealth.biomedcentral.com/articles/10.1186/1471-2458-8-225>



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Sunscreen is not listed as an essential medicine in Eswatini as a result it is not accessible free of charge to children with albinism in public hospitals and clinics. In the few instances where public hospitals issue free sunscreen they source the sunscreen from donors and do not purchase it themselves leading to sporadic availability. In the absence of the government providing free sunscreen most families of children with albinism, the majority of whom live below the poverty line, struggle to buy the sunscreen themselves for their children. A bottle is estimated to cost 150 SZL, making it out of reach for many. Families end up using vaseline petroleum jelly and other affordable but ineffective ointments as a sunscreen. The responsibility to ensure children with albinism from impoverished households access sunscreen thus ends up falling on organisations representing persons with albinism such as the Swaziland Association of Persons with Albinism, who source sunscreen from donors and private companies to distribute to their constituencies. Most hospitals and NGOs in Eswatini are found in urban areas, making it even more difficult for children with albinism in rural areas to access sunscreen.

The hospitals are also not well equipped to undertake skin cancer screening, testing and treatment, and dermatologists are in short supply (there is only 1 dermatologist in Mbabane) resulting in patients with albinism who are in need of intensive skin cancer treatment being referred to the Phalala medical referral fund.<sup>18</sup> The fund, which assists citizens who would otherwise not have access to specialist medical care, to secure such care either within Eswatini or, in special circumstances, outside Eswatini, has enabled persons with albinism to receive chemotherapy in South Africa. However, critics have pointed out that only a small number of persons with albinism benefit from the fund, leaving most people without timely and quality health interventions and the model is not sustainable.

### *Stigma and discrimination in accessing healthcare:*

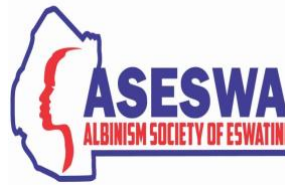
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<sup>18</sup> <http://www.gov.sz/index.php/component/content/article/101-health/services/574-phalala-medical-referral-fund>





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The Albinism Society of Eswatini has observed in its work that many persons with albinism in Eswatini and their families continue to experience stigmatizing attitudes and behaviours by healthcare providers when they seek treatment. Persons with albinism who present at the health care facilities with skin damage instead of being provided with the requisite treatment are often humiliated and scolded for not taking care of themselves. Mothers of children with albinism who seek treatment for their children for skin lesions are often accused of being negligent and failing to take care of their child. The insensitivity of health workers can be attributed in part to a lack of awareness and understanding of the lived realities of persons with albinism in the country.

#### *Insufficient health information on albinism:*

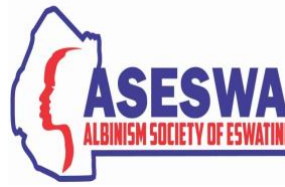
Research shows that many mothers of children with albinism in Eswatini do not obtain adequate health-related education about the cause and care of albinism at the birth of their child. The midwives who are often the first contact with babies with albinism sometime lack the knowledge to provide sound advice on albinism to the mother of a child with albinism. Mothers therefore do not adopt and teach their children the appropriate sun protective behaviour. In other cases, they adopt and pass on erroneous life-threatening beliefs shared by their community such as letting their child play in the sun without protective clothing for prolonged periods in the hope that this will help them adapt to the sun.

#### **Article 28 Right to education of children**

This Committee noted in previous concluding observations to Eswatini that children with disabilities in Eswatini in general have been historically marginalised and have not been able to access education opportunities on an equal basis to their non-disabled



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peers.<sup>19</sup> The advent of free primary education in Eswatini has seen an increased number of children with albinism attending primary school. However, despite the fact that Eswatini has sought to explicitly define and explain inclusive education in its policy frameworks students with albinism who attend mainstream school are often not accommodated resulting in many students with albinism dropping out of school after primary education. Children are not provided with low vision support to maximize the use of their vision such as standing or hand-held magnifiers, special reading glasses and text books and other materials in large font size. No costs adaptations such as having the student sit at the front row in class, providing them with notes of material written on the blackboard are often overlooked. They are often excluded from physical education on the basis of their low vision.

Students also experience bullying and stigmatisation within the school setting which also increases dropout rates. Students with sun burns and second stage squamous cell cancers experience greater stigma. The school often do not provide avenues for the students to speak about the trauma, humiliation and pain experienced and receive the necessary psychosocial support. With only a primary school education child with albinism end up working in low skilled outdoor jobs in their adulthood that increase their risk of getting skin cancer.

### Article 26 Right to social protection & security

The Department of Social Welfare administers a public assistance programme, which provides means-tested benefits to the needy or destitute in the country.<sup>20</sup> Those who benefit are mainly the elderly, widows, persons with disabilities and those who are terminally ill. Assistance ranges from E40.00 to E65.00 (Approximately US\$ 4 to 6.50) per month and is usually paid out on a quarterly basis. Social workers estimate

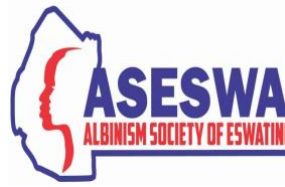
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<sup>19</sup> Committee on the Rights of the Child, 'Consideration of Reports Submitted by States Parties under article 44 of the Convention initial report of States Parties due in 1997 Swaziland' - CRC/C/SWZ/1 (2006).

<sup>20</sup> Committee on the Rights of the Child, 'Consideration of Reports Submitted by States Parties under article 44 of the Convention initial report of States Parties due in 1997 Swaziland' - CRC/C/SWZ/1 (2006) para11.



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that about 40 per cent of the population is needy and yet less than 10% are eligible to access this programme.<sup>21</sup> This suggests many children with albinism could be falling through the cracks. In the last two years as Eswatini introduced several measures to deal with the Covid 19 pandemic and its implications on socio-economic rights authorities have not always ensured that measures to respond to COVID-19 are inclusive and mindful of the specific needs of children with albinism, including the need for children with albinism to access to social protection to maintain their health, safety, dignity, and during and post the COVID-19 pandemic.<sup>22</sup>

### Recommendations to the Government of Swaziland

We appreciate the effort made by the government of Eswatini to give effect to the rights of children set out in the Convention of the Rights of the Child through the enactment of laws and policies to protect the rights of all children. The rights of the child are covered under Section 29 of the Constitution of the Kingdom of Swaziland 2005. This section affirms amongst others the importance of the right to health, education, and development of children. The country has enacted the Children's Protection and Welfare Act 2012<sup>23</sup> which seeks to provide protection for children from abuse and to promote their welfare. Eswatini adopted the Persons with Disabilities Act in 2018 which specifically addressed some of the issues affecting children with albinism. However, a lot needs to be done in terms of implementation of these progressive laws and policies.

### Preserving the right to life and upholding freedom from torture & inhuman and degrading treatment & punishments and ensuring access to justice

- The government of Eswatini should continue to strongly condemn the incidences of attacks and related forms of violence, including killings,

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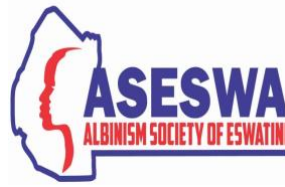
<sup>21</sup> Extract from Eswatini revised country report <http://www.rodra.co.za/index.php/eswatini-country-reports/31-countries/eswatini/80-revised-country-report-eswatini-swaziland> Simangele Daisy Mavundla.

<sup>22</sup> Ibid.

<sup>23</sup> African Child Policy Forum, 2021 CPWA 2012.



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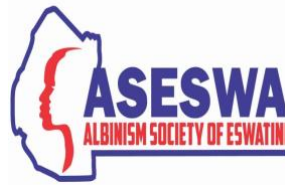
mutilations against children and other persons with albinism in the country;

- The government of Eswatini is called on to work with other SADC leaders to develop a regional strategy to promote regional cooperation for the prevention, detection, investigation, prosecution and punishment of cross-border crimes affecting persons with albinism in the region, notably trafficking of persons, children and body parts. To this end we specifically urge Eswatini to strengthen cross-border police cooperation through bilateral and multilateral agreements and to allocate adequate resources to better tackle trafficking in persons and body parts of persons with albinism;
- The government of Eswatini is encouraged in consultation with persons with albinism to develop, adopt and implement National Action Plans on Albinism to ensure the effective protection and promotion of the rights of persons with albinism with particular attention to children and members of their families. Eswatini is urged to allocate dedicated budgets to ensure the implementation of this National Action Plans on Albinism and other programme interventions on albinism and develop robust monitoring and evaluation frameworks to track progress;
- To ensure access to justice for children with albinism immediate and impartial investigation of attacks against children with albinism should be conducted to curb the delay in the delivery of justice in the criminal justice system.
- Child victims of such attacks should be provided with pro-bono legal representation. The Government should provide adequate protection to witnesses and victims.

### **Public Awareness:**



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- The government of Eswatini, civil society organisations and communities of people with albinism and other key stakeholders should work together to address root causes of discrimination and violence against people with albinism in Eswatini and increase knowledge and awareness on albinism including by embarking on an intense nationwide public awareness raising campaign to debunk false myths and beliefs about albinism and its cause.
- Government should support civil society working on issues regarding persons with albinism and should assist persons with albinism in awareness-raising about their rights including national mechanisms available for their protection.

#### Education:

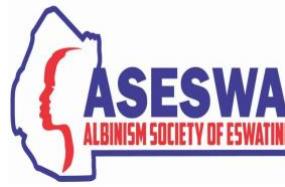
- Eswatini should take all measures necessary to enhance access to inclusive, equitable and quality education of children with and to provide comprehensive reasonable accommodation at all levels of education for children with albinism, including in the form of low vision support to maximize the use of their vision;
- Teachers and educators should continue being educated on albinism and proper protection as well as accommodation of the impairment of students with albinism in their care;
- Ensure that resources are at the disposal of schools to meet the specifications needed of persons with albinism, notably by providing textbooks and exams with larger fonts and assistive devices for low vision to read the blackboard.

#### Health:

- We specifically call upon Eswatini to ensure access to health services and health goods such as visual aids and appropriate sunscreen for all persons with albinism particularly in rural areas and with emphasis on skin cancer



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screening, prevention and treatment as well as specialist services for low vision and dermatological care. Psychosocial support should also be made available to person with albinism in their communities;

- The Eswatini government should, at a minimum, provide free sunscreen of an appropriate protective spectrum to enable persons with albinism to participate as equal members of society in daily life, and to enjoy their rights to health and life.
- Adequate, accessible and affordable diagnostic, preventative and curative skin cancer treatment should be provided to all persons with albinism.
- The Government should subsidize costs for accessing skin care and low vision health services for persons with albinism, as well as removing barriers to access to dermatologists and optometrists specialized in albinism.
- Nurses and midwives should be trained on albinism and provision of counselling to parents where babies with albinism are born. This will reduce chances of rejection and abandonment of mothers of persons with albinism.
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#### **Data collection:**

- We urgently request that Eswatini systematically collect, disaggregate, and disseminate data on children with albinism;

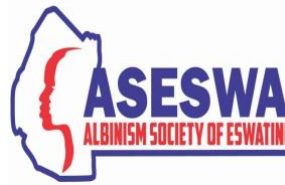
#### **Social protection:**

- We urge Eswatini to design, implement, strengthen social safety net mechanisms and programmes that are inclusive of children with albinism.

#### **Cooperate with Special Procedures:**



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- We implore Eswatini to cooperate fully with the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism and the AU Special Envoy on Albinism (once appointed) in the discharge of their mandates and to give serious consideration to implementing their recommendations, to provide the mandate holders with all necessary information relating to the mandate and to react promptly to their communications and urgent appeals in order to enable them to fulfil the mandate effectively;
- The Eswatini government should implement fully the provisions of the Persons with Disability Act of 2018 and the Disability National Plan of Action 2017-2021 which both contain provisions that protect the rights of persons with albinism.