

NATIONAL ALBINISM CONFERENCE

25-27 October 2013

'Noticed by many, but truly seen by few'



*Together, through action,
we can make a difference*

EKURHULENI DECLARATION ON THE RIGHTS OF PERSONS WITH ALBINISM



women, children &
people with disabilities

Department:
Women, Children and People with Disabilities
REPUBLIC OF SOUTH AFRICA



ASSA

ALBINISM SOCIETY OF SOUTH AFRICA

FIRST NATIONAL CHILDREN WITH ALBINISM CONFERENCE

Ekurhuleni, 26-27 October 2013

RESOLUTIONS

We, the delegates at the first National Albinism Conference, constituting more than 300 persons with albinism and disability rights activists, gathered in Ekurhuleni, Gauteng, South Africa

Therefore resolve that

On The Protection and Promotion of the Rights of Persons with Albinism

1. The SA Human Rights Commission should institute an investigation and research into the incidence of human rights violence against persons with albinism, including infanticide and human trafficking, in South Africa;
2. A register to document incidents of human rights violations perpetrated against persons with albinism in South Africa, should be kept;
3. Legislation should be strengthened/developed to outlaw hate speech and enforce action against violation of rights of persons with albinism.

On The Right to Self Representation

4. The national, provincial and local structures of the Albinism Society of South Africa should be strengthened with organisers at all three spheres, with government support;
5. Marches at national, provincial and local level should be organised by ASSA to raise the visibility of persons with albinism and to demand that the rights of persons with albinism be recognised and protected;
6. The Department of Arts and Culture should ensure that the book "Understanding Albinism" is available in all public and school libraries of South Africa;

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7. Persons with disabilities are encouraged to join civil society structures, including Disabled People South Africa, to empower themselves and as platform to bring about change.

On Reducing Personal Costs related to Albinism

8. Persons with albinism should be able to access subsidised/free services and products that will reduce the risk of secondary disabilities and disease;
9. A review of access criteria to care dependency and disability grants is required to determine why it is so difficult for persons with albinism to access grants;

On Equal Access to Health Care Services

10. Free access to health care services for persons with disabilities should be de-linked from disability grants and made available to all persons with disabilities, including persons with albinism;
11. The Department of Health and provincial health departments should provide free access to adequate and sufficient sunscreen protection;
12. The Department of Health should accelerate the roll-out of free eye tests and issuing of spectacles across all provinces;
13. The Department of Health should initiate negotiations in partnership with the Albinism Society of South Africa with the Council of Medical Aid Schemes for the inclusion of sunscreen and other essential assistive device benefits as prescribed minimum benefits;

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14. The Department of Health should institutionalise training of all its medical and non-medical personnel to eradicate discrimination against persons with albinism, and to understand the different types of albinism and interventions required;
15. Access to discrimination-free health services in rural areas should be improved through, among others, roll-out of infrastructure.

On Equal Access to Lifelong Learning

16. Schools where learners with albinism are enrolled should be identified, with teacher empowerment and human rights programmes, as well as adequate support to these schools and learners, made available at the beginning of every school year;
17. FET colleges and universities should provide adequate and timeous support services to students with albinism.

On Equal Access to Skills and Economic Development

18. Barrier-free access to skills development programmes, entrepreneurship development and decent work programmes in rural areas should be accelerated;
19. We need to move beyond targets for employment equity, but focus on decent work and strengthen the fight against under-employment;
20. The focus on learnership programmes should not detract from the decent work agenda – persons with albinism want decent jobs and economic empowerment, and learnership programmes seldom lead to employment due to discrimination.

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On the Development of Rights-based Language, and Strengthening Social Cohesion

21. Persons with disabilities should be recognised as a particular vulnerable group to social exclusion due to the harmful beliefs associated with albinism, and all social cohesion programmes should therefore address this exclusion;
22. The media should pay particular attention to the manner in which they portray persons with albinism in their reporting, and the current trend of providing a platform for persons with albinism on television should be encouraged and accelerated.

On International Cooperation

23. The South African government should champion an item on the rights of persons with albinism for consideration by the Heads of State of the African Union;
24. The South African government should support the convening of a Pan African Conference of Persons with Albinism by organisations of persons with albinism on the continent.

On Children with Albinism

25. Children with albinism should enjoy specific protection from discrimination and exclusion;
26. Conference adopts the resolutions tabled by the Children's Conference as part of this Declaration.

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CHILDREN'S CONFERENCE

We, the children who have participated in the Children's Parallel Conference of the First National Conference on Albinism on 26-27 October 2013 at Ekurhuleni, Gauteng, have learnt that unity in action is a strength.

We have learnt that our cultural diversity makes us strong and special as a nation and that we should respect it at all times.

Therefore we should work towards unifying all our people on the issue of albinism so that we fulfil our constitutional rights as equal citizens of our country.

We have talked about many issues during this Conference. We have grown in creativity, knowledge and expressiveness and in our understanding of our roles as young people.

Therefore, resolved that

1. Better knowledge on albinism through awareness raising will lessen the discrimination we face in society;
2. Schools need to be better equipped, both in training of staff and the tools of teaching to fit the needs of learners;
3. We need to make social cohesion programmes in communities to encourage tolerance and respect for all;
4. By building on self-confidence, self-respect, self-image and self-representation we will become greater participants in our own lives and in the way we interact with society;
5. We encourage the establishment of a youth forum so that we can represent our views directly;
6. We should use media, especially social media to educate people and show them that we are as talented as anyone else in the world.