The Political and Civil Rights of People With Albinism
In the Democratic Republic of Congo

• This report is respectfully submitted by NGO Under the Same Sun in regard to the list of issues prior to reporting for the International Covenant on Civil and Political Rights on the Democratic Republic of Congo.

• Under The Same Sun (UTSS) is a civil society organization committed to ending the often-deadly discrimination against people with albinism. UTSS promotes, via advocacy and education, the wellbeing of persons with albinism who are misunderstood, marginalized, and even attacked and killed because of their genetic condition. While UTSS acts globally, much of our focus has been on the crisis faced by people with albinism in Tanzania.

Introduction

• On his 2010 track “Âme Seule”, Congolese hip-hop artist Junior N'kashh raps about violence and discrimination against people with albinism, a condition he also has: “This man that won't even shake my hand…dreams of cutting my testicles to make a talisman,” he raps. N'kashh’s song is about the attacks and mutilations perpetrated by those who sell the body parts of people with albinism, making bogus potions with the promise of good fortune to the buyer.

• Discrimination, marginalization and violence plague the lives of people with albinism in the Democratic Republic of Congo (DRC). Albinism is a genetic condition characterized by little or no pigment in the skin, hair and eyes. This lack of natural protection from the sun means most will die of skin cancer before reaching middle age. In the Great Lakes region, many believe that people with albinism are ghosts; a curse on the family and community; spirits that never die. Children with albinism are often abandoned. Mistaken beliefs in the magic of albinism have created a gruesome illegal market in body parts across the region. Low vision, structural barriers to education, employment and participation in society cause cycles of poverty. There is little popular knowledge about the condition. In this vacuum, superstitions thrive. While violence affects many, sun-related skin cancer is the largest killer of people with albinism.

• To a great extent, Congolese with albinism do not enjoy rights to life, liberty and security of the person.

• Often, Congolese with albinism are pejoratively called Ndundu (supernatural) or Tshitokatoka (other). They are at risk of severe isolation because the condition is widely misunderstood. Social stigmatization can
occur, especially within communities where other family members and the community have dark skin and appearance.

- The Mwimba Texas Foundation reported on the situation to the UN OHCHR in June 2013. The foundation, named for the famous Congolese wrestler with albinism who chairs it, described discrimination against persons with albinism in the DRC - in schools, on public transport, at the factory, at the office, in the community, in the family and within marriage. The foundation’s report described the practice of hunting intimate parts of persons with albinism for ritualistic / fetish practices as they are believed to bring good luck. This prejudice is also faced by the mothers of children with albinism, who are often abandoned by their partners and who frequently abandon their children with albinism. Discrimination across society keeps children marginalized from schools and creates cycles of poverty and barriers to employment for adults with albinism.³

What is Albinism?

- Albinism is a rare, non-contagious, genetically inherited condition characterized by a lack of pigmentation in the hair, skin and eyes. It occurs regardless of ethnicity or gender. Both parents must carry the gene for it to be passed on, even if neither have albinism themselves. In Africa, estimates on the incidence of albinism range from 1 in 5,000 to 1 in every 15,000. In some populations it may be as high as 1 in 1,000.⁴

- Almost everyone with albinism is visually impaired. The majority are “legally blind” and very sensitive to light. Eyeglasses can only partially correct this problem. While most can read large print and don’t require Braille, they cannot see a blackboard in a regular classroom. In most cases, structural barriers prevent full participation in society on an equal basis with others.

- With no melanin or pigment for protection, skin burns immediately in the sun. Most Africans with albinism have severely sun-damaged skin, often acquiring dramatic, visible skin damage at an early age.⁵ Fatal skin cancer will claim the vast majority before they reach 30 to 40 years of age. There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable in most African countries.

- In countries where the population has dark-coloured skin, hair and eyes, people with albinism stand out, making them targets of taunts, discrimination and dangerous myths.

Applicable Human Rights Instruments

- Until recently, international human rights instruments were silent about the

- The Constitution of the DRC provides rights that can protect citizens with albinism: Articles 11, 12, 13, 14, 15, 16, 60, 61(2).
- The government of DRC ratified the International Covenant on Civil and Political Rights in 1976, though its national implementation is still a work in progress.
- The most applicable section of the Covenant is not consistently enjoyed by persons with albinism in DRC. Part III, Article 6.1 states “every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.” Also, Article 9.1 states “everyone has the right to liberty and security of person,” rights not enjoyed by all Congolese with albinism.
- When the civil or political rights of an individual are violated, Part II, Article 3 of the Covenant compels State Parties to provide (a) an “effective remedy” which is (b) determined by “competent judicial, administrative or legislative authorities” which shall (c) “enforce such remedies.”
- While the Covenant makes provisions for states of public emergency (Article 4.1) such as DRC has seen over the last two decades, it continues to have effect in protecting individuals from discrimination on named grounds.
- Article 20.2 states “any advocacy of national, racial or religious hatred that constitutes incitement to discrimination, hostility or violence shall be prohibited by law.” While not propaganda in the traditional sense, negative ideas about albinism are spread by the illegal body parts market as well as perpetuated through film and media.6

Violence Against Congolese with Albinism

- In DRC, there have been 14 recorded ritual killings, 31 attacks, one abduction and nine grave robberies in the past decade. Six Congolese with albinism have sought asylum, fleeing the violence.7 This is part of a wider pattern of murders and attacks across East Africa. Since 2000 there have been 512 reports of violence against people with albinism across 27 countries, including 190 killings, 322 abductions, mutilations, rapes and
grave violations. A corpse can be worth up to $75,000 US. These are reported cases only. The actual incidence of attacks is predicted to be much higher, given the limited available data.

- In the autumn of 2016 people have been leaving the village of Twangiza due to threats and warnings from unidentified sources.

- After armed men attempted to kidnap three children with albinism on several occasions, Lebon Matambiru, took his family into hiding. Matambiru told Africanews: “The file on the situation of my kids has not been evolving at the judiciary. That is why we have been living in hiding as we are afraid that we can be kidnapped at any time.”

- On August 5, 2014, a girl with albinism by the name of Namukyungu Byaombe was abducted and killed by unidentified attackers. Her body was found by police.

- Around midnight of April 27, 2015, a two-year-old girl with albinism narrowly escaped abduction in Kampene, Maniema Province. After noticing her daughter had disappeared, the mother screamed for help and her daughter was released by the kidnapper.

- On February 16, 2015, a two-year-old boy with albinism was abducted in Nyantende, Kabare territory, South Kivu. Kidnappers broke into the family home while the parents were out, enticing the boy with sweets and wrapping him in a bag. In mid-September, a trafficker of children with albinism was arrested for the abduction by the police in Kamanyola, Walungu territory.

- On February 4, 2015, the grave of Augustin Kerekwa was robbed. He was buried in the community of Nyangezi, South Kivu.

- In June, 2015, a man with albinism from DRC was granted secured permanent residency in Ireland through a non-asylum process. He suffered severe persecution and untreated skin cancer in DRC.

- Many girls and women with albinism are exposed to sexual violence due to the mistaken belief that having sex with a person with albinism can bring wealth or cure HIV/AIDS.

- The reporting, investigation, arrest, prosecution and conviction of the perpetrators of these crimes against Congolese with albinism remain rare. There has been little or no legal action on the following 23 DRC cases reported by the Association for Complete Promotion of People with Albinism. All of the following victims have albinism. Most are young people or children:
• Abdu Lushule, 40, of Idjwi Island, was the victim of an attempted abduction. His case was not prosecuted. The grave of Bihamaso Musongi on Idjwi Island was robbed. There was no prosecution. Kidnappers tried to abduct Bahati, 20, also of Idjwi Island. Her case was not prosecuted. Flavier Wetemwami’s grave in Bunyakiri was robbed – he died at 18. There was no prosecution. Kidnappers tried to abduct Desire Shamavu, 15, of Nyabibwe. They weren’t prosecuted. Iragi Badesire, 18, of Birava was killed, his body mutilated. Ishara Magalamuk of Kavumu died at 23. His grave was robbed and nobody was prosecuted. Claude Lwahimbwa, 27, of Katana, survived an attempted abduction. Kidnappers were not prosecuted. Attackers tried to kidnap and rape Dama Lwahimbwa, 24, of Katana. They were not prosecuted. Claire Ndunda, 35, of Bukavu was killed. There was no trial. Kidnappers tried to abduct Yohali Tambwe, 22, of Bagira. There was no trial. Muba Cubaka, 37, of Bagira, also survived an abduction attempt, but it did not go to trial. Mwati Masoka Clarice, 15, of Bukavu, was threatened with death. There was no trial. Augustin Kerekwa’s grave in Nyangezi was robbed. The case against the perpetrators was corrupt. Aganze Kerekwa, 30, of Nyangezi received a death threat, but his case was suspended. Chance Mwengeelelwa, 15, of Kamituga was killed and mutilated. The case against his murderers was corrupt. Vumilia Walubila, 28, of Kitutu was abducted and is missing. Her kidnappers have not been prosecuted. Biyamungu Kayumba, 35, of Fizi was threatened with death. There has been no trial. Kidnappers tried to take Balongelwa Akikwa, 28, of Fizi. They have not been brought to trial. Shukuru Lukilika, 9, of Fizi survived an attempted abduction, which was not prosecuted. Huruma Koko, 32, of Uvira, survived an attempted abduction, which was not prosecuted. Alphonse Kakirha, 17, of Uvira, was killed. His murder has not been prosecuted. Twelve-year-old Jeanine Byamungu of Uvira was killed, her body mutilated. Her murderers have not been prosecuted.

• L’Association Pour la Protection et le Developpement de la Personne Albinos provided the following as examples of cases they received in Mbuji-Mayi, Kasai-Oriental Province: Kalonji Aron, 15, was killed on February 22, 2012. The attempted murder of Ntumba Gertride took place on July 8, 2013. Junior Katambwa was assaulted on May 12, 2013. Prince Beluba was assaulted. Alnor Tshipwaka, 20, was assaulted. Aruna Kanyemba, 14, was driven from her home. Beatrice Mujinga was accused of being a witch and driven from home.

• Further examples come from Bas-Uélé district: Matena Gedeon was 12 and orphaned when he was driven from his uncles and accused of witchcraft. The parents of Twakaidi Policarpe refused to enroll him in school because of his albinism. Monga Mendolo Aron, 23, was assaulted. A four year old and her mother were hunted because she was a child with
albinism. In Mwega, a six-year-old child was abducted on February 26, 2009. After six days the child was found dead, missing limbs.

- Between November 18, 2012 and July 10, 2013, teacher Jean Louis Gbangbi Ngoza experienced attempted murder and assault in Kisangani. Two mothers, Véronique Akambo and Noella Kasongo, were rejected by their community for giving birth to children with albinism. Farmer David Olonga escaped an attempted murder in his field by armed attackers in Bukavu, South Kivu. In the plain of Ruzizi, Uvira territory, the grave of a person with albinism was desecrated in 2011, the bones and hair stolen.\(^{18}\)

- There are likely many more cases, since many go unreported. UTSS gathers information on the situation of people with albinism in DRC via the testimony of witnesses and survivors, police reports, academic research, field observation of organizations on the ground in DRC and also through credible journalistic accounts.

- According to Reporters Without Borders, DRC scores poorly on the Press Freedom Index, coming in at 152\(^{nd}\) out of 180 countries measured: “Freedom of information is constantly violated in Democratic Republic of Congo,” RWB’s website says. “Journalists are exposed to threats, physical violence, arrest, prolonged detention and even murder. The main perpetrators – the army, police and security services – enjoy complete impunity.”\(^{19}\) This can impact information available to UTSS from government, police and journalists about attacks on Congolese with albinism.

Recommendations

**Invest in education**

- The Government of DRC should invest in education for people with albinism. Education is the key to future indoor employment and the associated possibility of avoiding a short life expectancy due to skin cancer. Spaces within safe, supportive, nurturing environments should be made available for children with albinism. Local albinism civil society organizations should be enlisted to help identify candidate children for this initiative.

- The Government of DRC should consider as a model the UTSS Education Program, which funds education for 300 Tanzanian children with albinism, from kindergarten to graduate studies. This number represents only a small fraction of children with albinism in need of such opportunities. UTSS covers personal expenses, school supplies, uniforms, medical services (regular dermatology and optometry examinations) as well as sun protective clothing, sunscreen lotion and low vision devices.
• Learning opportunities for children with albinism should be monitored to ensure the environment is free of abuse and that students’ health, education and social well-being is being looked after. UTSS follows up to ensure staff, administrators, teachers and other children have a good understanding of albinism.

**Train educators**

• The Government of DRC, in consultation with local albinism civil society organizations, should develop appropriate training for educators (teachers, administrators, staff, etc.) specifically suited to responding to the needs of children with albinism.

• Training should also make educators aware of the particular low-vision needs of children with albinism. Being legally blind is a physical disability and entitles one to reasonable accommodation at school. Large print, glasses, magnifying glasses, monoculars and specialized computer equipment are helpful to most children with albinism.

• The student should be consulted on the best vantage point in a classroom from which to see i.e.: proximity to the blackboard; from the right, left or center, and out of bright, direct light. Blackboard notes, exams, assignments, etc. should be made available in appropriate print sizes. Extra time should be provided for written exams – an additional 50% is suggested. Providing a level academic playing field for children with albinism can help mitigate bullying.

• Training should also make educators aware of the specific sun protection needs of children with albinism, such as: sunscreen lotion with Sun Protection Factor (SPF) of 30 or more; wide-brimmed hats and sun-protective clothing like breathable long-sleeved shirts with high collars, long trousers, and long skirts, and; sun-avoidance in shade or in-doors. Implementing these measures should be done in such a way as not to compound a child’s marginalization.

**Collect data**

• The Government of DRC should investigate, collect and publish data about attacks, murders, abductions, assaults and other incidents involving Congolese with albinism. As well, information should be kept on investigations, arrests, charges, prosecutions, trials and convictions for perpetrators of violence against people with albinism. Information on attacks is sparse. Better data is needed. Albinism NGOs in East Africa have limited capacity to investigate reports. These NGOs also have concerns for the security of their own staff with albinism.

• Albinism NGOs should be funded to collect data to increase response rates and build confidence among the population with albinism. Data
should be stored securely, so as not to provide information for those interested in profiting from the trade in body parts of persons with albinism.

**Raise awareness**

- The Government of DRC should work with albinism civil society groups to build on the success of awareness-raising campaigns conducted in recent years, such as the public service announcements on TV which aired across East Africa in the lead up to June 13, 2015, the first International Albinism Awareness Day.\(^{21}\)

- In 2008, the United Nations Development Programme and the Association for the Protection and Development of Albino People in Orientale province, sponsored a workshop of 250 people with albinism and others in Kisangani. The purpose was to raise awareness about discrimination and marginalization around the condition among NGOs and funders.\(^{22}\)

- A high profile individual with albinism such as DRC hip-hop artist Junior N'Kashh or wrestler Mwimba Texas could be approached to act as a spokesperson for such efforts.\(^{23}\)

- Emphasize awareness-raising activities in rural communities as well as those that border countries where attacks are more frequent. This could counter discrimination and stigma and trafficking in body parts. It could also encourage reporting.

- Albinism awareness TV and radio spots, seminars, “in-person” encounters and public health campaigns should be produced to raise awareness about the condition and its stigma and to humanize and normalize albinism. Family members, legal guardians, caregivers, youth, schools, labour organizations, communities, community leaders, the media and other civil society organizations should be targeted with de-mythologizing messages about human dignity and respect, focusing on simple medical explanations, offering easy ways to live with and care for the condition.

**Empower youth**

DRC should work with albinism civil society organizations to support confidence-building workshops for youth with albinism along the lines of the “Stares, Smirks and Shout-outs” seminars put on by the US National Organization of Albinism and Hypopigmentation.\(^{24}\)

**Protect Health**

- The Government of DRC should make sunscreen and sun protective garments more readily available to Congolese with albinism. The vast majority of Africans with albinism will die from skin cancer. Sun protection awareness and materials are urgently needed.
• The Government of DRC should immediately cease any taxation of sunscreen as per the Africa Albino Foundation recommendation.25

• Even untaxed, sunscreen is prohibitively expensive and hard to access for most that need it. Sunscreen should be imported or manufactured and subsidized by the Government of DRC. Distribution should occur in partnership with albinism civil society groups like the Association for Complete Promotion of People with Albinism and L’Association Pour la Protection et le Developpement de la Personne Albinos.

• The government should fund local production of sun protective garments.

• UTSS helped operate a local sunscreen production unit and a garment manufacturing shop at the Regional Dermatology Training Centre, Kilimanjaro Christian Medical Training Centre, in Tanzania. Persons with albinism are employed at this facility. UTSS is available to provide advice to DRC about creating such local indoor employment opportunities that produce sun protection clothing.

• UTSS congratulates DRC on the success of International Albinism Awareness Day 2015 where the opportunities were made available for 500 free consultations in dermatology and ophthalmology for people with albinism in DRC26 and distribution of sun protection equipment to 500 people with albinism.27 UTSS encourages the Ministry of Health to partner with and support further efforts of L’Association Pour la Protection et le Developpement de la Personne Albinos in this regard.

• The Government of DRC could also consider as a model the health services of Standing Voice, a Tanzania and UK-based NGO with a specialization in mobile clinics targeting low vision and skin care in both rural and urban settings. Standing Voice could provide requisite training to health care providers such as optometrists, ophthalmologists and dermatologists in DRC.

Partner with NGOs

• Civil society groups and NGOs are partners in the successful implementation of any of the above recommendations. Thus, their activity should be enabled.

• NGOs like Under the Same Sun and Standing Voice can be key partners for the Government of DRC as well as local actors like the Association for Complete Promotion of People with Albinism, Association Pour la Protection et le Developpement de la Personne Albinos and Fondation Mwimba Texas.

Change Policy
• UTSS supports the call of L’Association Pour la Protection et le Developpement de la Personne Albinos for a law for the protection and promotion of persons with albinism in the DRC, including their civil and political rights.  

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• The government of DRC should consider the suggestion of the UN Independent Expert On The Enjoyment Of Human Rights By Persons With Albinism to create a task force on albinism consisting of members of various relevant ministries: disability, education, justice, health among others. This task force could help government in carrying out its short to medium term goals and assist in implementing other recommendations made in this report. Such a task force should be appropriately resourced and include civil society groups and people with albinism.  

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• The government of DRC is urged not to ban peaceful demonstrations or meetings. These are important tools for organizing change and challenging stereotypes and beliefs that are harmful to people with albinism in DRC.  

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1 Junior N’Kashh, “Âme Seule.” YouTube, November 12, 2010  https://www.youtube.com/watch?v=f0ASCo3i0-I accessed May 12, 2016


7 Under The Same Sun (UTSS) Canada & Tanzania "Reported Attacks of Persons with Albinism – Most Recent Attacks Included" April 15, 2016  http://www.underthesamesun.com/ accessed May 12, 16

8 Under the Same Sun (UTSS) Canada & Tanzania "Reported Attacks of Persons with Albinism (PWA) – 1 Page Summary" March 3, 2017
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11 Report from Mr. Jean De Dieu Kwimbonera, Police Commander at the PNC of Baraka


14 Source: Mr. Lushole Jonena, chairperson of DRC’s Association For Complete Promotion Of People With Albinism (APIA), South – Kivu, DRC. The information was collected from APIA and sent to UTSS in July of 2015 by BBC Journalist Byobe Malenga;

15 UTSS was informed via a personal contact from this person’s sister who now resides in Canada.


17 Association for Complete Promotion of People with Albinism (APIA) South – Kivu, DRC “PWA Attack Cases from South Kivu DRC” July 20, 2015

18 Servain Ndumba Matombi, Coordonnateur National, Association Pour la Protection et le Developpement de la Peredonne Albinos « Quelques Cas De Tueries Et Agressions Dont Ont Ete Victimes Les Personnes Albinos De La Republique Democratie Du Congo » Kisangani, le 22 Août 2013


21 A/HRC/26/L.7 International Albinism Awareness Day


26 Agence Congolaise de Presse « Province Orientale : des consultations ophtalmologiques et dermatologiques gratuites pour les albinos » June 12, 2015
27 Association Pour la Protection et le Developpement de la Personne Albinos « Programme des Activities Marquant la Celebration de la 1ere Journee Internationale de la Sensibiliosation a l’Albinsme en RD Congo » June 13, 2015
28 Ibid Association Pour la Protection et le Developpement de la Personne Albinos 2015
29 Report of the UN IE during 31st ordinary session of the UN Human Rights Council, 4 March 2016