

Security Guideline for People with Albinism

Concrete and specific security measures to prevent and handle attacks on people with albinism

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UNITED NATIONS INDEPENDENT EXPERT PERSONS WITH ALBINISM



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Warning. Some of the content of this document may be **unsuitable to be read by children**. This guide could also prove to be traumatic reading for someone who is at risk. Please use and filter the content for appropriate audiences.

Some key statements are **enhanced in bold** to improve readability for people with visual impairment.

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Foreword

I have been utterly shocked at the reports of physical attacks against hundreds of persons with albinism across 27 countries in the last 10 years. Attacks have resulted in death, mutilation and trauma in many cases. Moreover, these numbers are reported cases alone. It is believed that many cases go unreported for various reasons including the involvement of family members and the lack of formal monitoring mechanisms to keep track of, and report accurately on all cases. The situation is highly concerning. Thankfully efforts to end these attacks are now underway including through the creation of my mandate by the United Nations Human Rights Council. Under this mandate, I have begun working with various stakeholders on developing effective responses including developing specific protection and prevention measures that could be easily implemented in the context of developing countries – the setting of a majority of these attacks.

It is in this regard that I welcome these Security Guidelines for People with Albinism by CBM. It gives practical tools of self-protection to persons with albinism while providing guidance to teachers and other caregivers. With the

expertise of CBM in the area of persons with vision impairment – an impairment in most persons with albinism – these Guidelines are well-suited to the context. They are also bound to equip communities with basic but effective tools for protection of their members with albinism. This in turn will contribute to the eradication of the real and palpable fear that has crippled persons with albinism and their families in the wake of attacks. I believe that these Guidelines should be part of advocacy among persons with albinism as well as basic security training for all caregivers of persons with albinism in all countries affected by attacks and stigma. I look forward to its wide distribution and use.

Ikponwosa Ero

United Nations Independent Expert on the Enjoyment of Human Rights of Persons with Albinism

For many decades CBM has been supporting programmes for people with a visual impairment. Among our clients, we have met many persons with albinism; we have heard their stories, have worked together to mitigate their challenges and have rejoiced in the opportunities they have taken up to bring positive change in their lives and communities. We are deeply concerned to see and hear that appalling violence against persons with albinism is still taking place today.

We sincerely hope that this guideline will empower people, parents, schools and communities in protecting people with albinism so that each person can reach his or her full potential.

David Bainbridge

International Director CBM





Introduction

Violence against people with albinism has been taking place for many years: bullying, name-calling, family abandonment and structural discrimination across all levels of society have been reported. Recently however, a particular trend of violence has been observed. People with albinism are being targeted by criminals based on the superstitious and the deeply false belief that body parts of people with albinisms have magic powers when used in witchcraft and traditional medicine. This belief unfortunately is still rife in many parts of Sub Saharan Africa. There are also other dangerous beliefs including the myth that the body parts of children in particular are most efficacious for witchcraft and that sexual intercourse with a woman with albinism cures HIV Aids exists.

What is Albinism?

Albinism is a rare, non-contagious, genetically inherited condition which occurs worldwide regardless of race, ethnicity or gender. It most commonly results in the lack of melanin pigment in the hair, skin and eyes. Some effects of albinism include vulnerability to skin cancer and significant visual impairment. They also face various form of abuses and more recently, physical attacks. Both parents must carry the gene for albinism for it to be passed on to their children, even if they do not themselves have manifestations of the condition. The prevalence of albinism varies worldwide. According to the WHO, estimates vary from 1 in 5,000 to 1 in 15,000 people in Sub-Saharan Africa with particular groups having a higher average occurrence of 1 in 1,500. In Europe and North America, estimates are 1 in 17,000 to 20, 000 people have the condition.

This violence, often leads to traumatizing, maiming and killing of people with albinism. It happens at a local level by perpetrators (sometimes with involvement of a relative). Body parts are reportedly worth high amounts of money on the black market within affected countries. However, some cases indicate cross-border activity which warrants calls for a coherent security strategy both at the grassroots and regionally.

The **objective** of this <u>Security Guideline for People with Albinism</u> is **to provide concrete and specific advice to people with albinism as well as those working with them**, to remain safe within the context of where they live. It also provides easy to implement steps in handling an incident and swiftly mobilize useful resources to try and return a victim back to safety.

In Africa, people with albinism stand out because of their features, particularly their coloring and are thus easy to target. Many also struggle with visual impairments making them additionally vulnerable. The visual impairment often leads children with albinism to attend schools for the blind which again makes them easy to locate and target.

In its global operations, CBM has worked for several years on a Disability Inclusive Security Management and Security Training approach.

Sad reality

On 4 May 2013, various experts at the UN stressed that "in several African countries, it is believed that body parts of persons with albinism possess magical powers capable of bringing riches if used in potions produced by local witchdoctors. Some even believe that the witchcraft is more powerful if the victim screams during the amputation, so body parts are often cut from live victims."

Since the year 2000, civil society organizations report that there were almost 450 attacks on people with albinism in 25 African countries. More than 170 people were killed, many others mutilated or raped. Based on this experience and the input of many people with disabilities, different skills and techniques were developed. These involve incident avoidance and prevention but also a swift incident management system to assist vulnerable people in need.

We strongly believe that an inclusive and decisive approach towards the underlying problem, will result in stronger awareness, fewer incidents and swifter incident management. Although in some high-prevalence countries, attacks have been reduced, there is no room for complacency because little has been done to address the

context that facilitated these attacks including misbeliefs about albinism. Crossborder criminal activities and trafficking may simply shift the problem elsewhere.

With growing awareness, training and measures put in place:

- **Individuals, parent-teacher groups and guardians** will be empowered to recognize contextual challenges and guide an appropriate response.
- Children with albinism will recognize danger early and act swiftly.
- **Peers will take responsibility** for each other and find safety in being part of a group.
- Extended families will take responsibility for safe arrival at school and at work.
- **Guards at schools and institutions** will be able to detect early on whether people with bad intentions are watching to detect an easy victim.
- **Managers** will act swiftly when an incident occurs.
- **Communities** can be mobilized when an incident occurs.
- Community and religious leaders will strongly condemn practices and incidents and mobilize resources to deter and solve them.

Basic surveillance detection Learn to be aware of your surroundings. Notice things and events that seem out of the ordinary, for example:

"I have seen this man several times before. Why is this person / car following me from a distance? Why is this person asking me where I live? Why are these three people sitting in an idling car near my house when I get off the school bus?" We invite you to **read these guidelines and decisively implement quick**, **easy and inexpensive measures to help safeguard children and people with albinism.** In doing so, you could be instrumental in protecting precious lives and making a genuine difference in the lives of people with albinism.

Please share this publication within the UN, NGO and People with Albinism and Disabled People's Organisation networks as well as within Human Rights circles.

Should you have further questions about Safeguarding People with Albinism, Disability Inclusive Safety & Security Training, NGO Security Management systems or Crisis Management training, please contact <u>hssunit@cbm.org.</u>

Security guidelines for children with albinism

Children with albinism are perceived to be at higher risk. They are young, not so physically strong and due to their vision impairment, may not readily observe that they are being watched or followed. As many of them will go to school based on a regular pattern (time, uniform and route), they are easy to spot, follow and target, particularly in isolated locations. Some parents have even decided to take their children with albinism out of school so that they have to worry less about their safety going to school.

Rainy season

One family living near Lake Malawi commented on the added dangers during the rainy season when children, returning from school, seek shelter in huts if they are caught in downpours.



Security Guideline for People with Albinism

Below are several concise action steps that should be discussed with children with albinism, their families, caretakers and those with whom they study.

- Avoid walking to school alone. Always make sure that you go to school and back home with several trusted friends whose task it is to ensure that you arrive safely.
- Set up a school companion system where responsible and trusted peers are teamed up with pupils with albinism to assist, keep them safe and 'be

Resisting kidnap

Normally security professionals advise victims **not** to resist during a kidnap attempt to increase your chance of survival. However, the motives for kidnapping a person with albinism is motivated by the value of their body parts and thus often ends in death. In this case, it is recommended that, when somebody tries to take you against your will, you **fight and scream** for help in the hope that your noise and struggle will alert others to come to your aid. A fighting and struggling victim <u>may</u> coerce kidnappers to abandon their attempt. You may get hurt, but you increase your chance of survival.

their eyes where needed' to spot possible surveillance.

- Where feasible, **vary the times you go to school/home/do your chores**, use different routes and avoid predictable routines.
- Avoid quiet, deserted roads or routes. Be outside only in the daylight.
- Learn to practice situational awareness and basic surveillance detection.
- **Carry a whistle on a cord around your neck** and blow it loudly when you need help or feel uncomfortable.
- Learn to trust your instinct if something does not feel good, there often is a reason for it. Act on it firmly and without hesitation.
- **Do not accept a lift**, not even from somebody that you know somewhat. Use good judgment, be wary of people's motives even when somebody says, for example, "your mother has sent me to pick you up."
- Watch out for strangers or people who have a special interest in you and avoid contact with them.
- Practice basic 'travel tracking': Tell a trusted friend where you are going, how and when you plan to arrive. If you have a mobile phone, send a short message when you depart/arrive (e.g on WhatsApp). Ask your friend to monitor, and where needed raise an alert, when you do not arrive at the agreed time and place.
- On routes that you travel regularly, know where there is a safe place you can go should you feel threatened or uncomfortable with a situation.

July 2016, Tanzania

An inclusive secondary school in Tanzania has 15 students with albinism in a residential setting. The head master explains: 'The school is large (70 teachers and over 1400 pupils) and they are all sensitized to the need of watching out for their peers with albinism. They are their 'eyes'.

For school managers

- Ensure that school bus drivers and watchmen are well trained and specifically tasked to watch over the security of children with albinism
- Ensure all children **know how to raise an alert** and know who to contact when an incident occurs.
- Consider doing a basic assertiveness course with all children and teenagers where they learn to be firm, know the boundaries of decency and signs of danger and are equipped to raise the alarm. This could include some very basic self-defense techniques as a last resort.

Albinism and Hearing, Tanzania

It was found that an above average number of students with albinism also had hearing difficulties. To enhance their ability to scan the environment for possible danger, hearing tests and appropriate devices are important.



The information above is geared towards children. However, the advice provided is also valid for women or people who are otherwise vulnerable due to disability.

Counter surveillance

In the text above, some basic principles are outlined to help children spot things that are out of the ordinary. **It has been proven that most criminal acts are preceded by a period of observation**. Criminals generally do not strike opportunistically. **They lower their risk of detection and arrest by seeking a vulnerable, easy target.** They seek to increase their chance of success by getting to know an area, seek out a soft target, get to know his/her routine and strike at a place and time where the person is vulnerable, unaware and unprotected. Security Guideline for People with Albinism

A criminal gang may cruise around an area that is considered target rich, such as a school where many pupils with albinism attend or a project or office where men and women with albinism are employed or where they regularly meet. They may sit in an idling vehicle near a school exit to see who leaves and when. They may follow somebody from a distance to get to know his or her routine.

With basic training, (school) guards, drivers and other trusted people nearby can learn to spot surveillance.

Gate staff must be instructed to be alert and aware, patrol their area of

Safe residence

There have been reports of small groups armed with machetes appearing at night at a house seeking to kidnap a person with albinism. What they are looking for is a swift and silent getaway. Consider this and see how you can make your house a difficult place to get into. Find a way to deter these people (good locks, a big dog, strong door or a safe room) and raise the alert through a simple alarm system. Agree with neighbors that you will look after each other.

responsibility and act decisively when they observe possible surveillance. They must know at all times how and with whom to raise an alert, share a suspicion and take protective measures for the people under their care.

Security guidelines for families

When you have a family member with albinism, it is important to be alerted to the reality and to be aware of dangerous trends and patterns. Never assume that danger and sorrow will not come to your family.

Unfortunately, some people with financial or superstitious motives and a complete lack of conscience will see your family member as a possible source of quick wealth and fortune. From incident analysis, there is also evidence suggesting that some disappearances of people with albinism were orchestrated by or at least had a level of involvement from a family member or neighbor who knew the family routines and points where they were vulnerable.

We therefore urge parents to have an open dialogue around albinism.

- Treat your children with albinism well, learn about their needs and know how to explain what this inherited (genetic) condition is (and is not) to those around you.
- Discuss openly where you may be vulnerable and take decisive action.
- Mobilize the (religious) community as well as your trusted, extended family and collectively work out how your precious family members with albinism can be safeguarded while still staying active in community life.

Situational awareness

You can be 'the eyes' of a person with albinism by having the ability to identify when potential targeting activity is taking place. Watch for absence of the *normal* and presence of the *abnormal*. Your children with albinism are precious and can make wonderful contributions to the community. So, please protect them so they can reach their full potential.

Take note of the measures suggested in the previous chapter.

- Pro-actively assess how your family can go about daily routines, chores, safe movement and travel.
- Ensure safe transport is available or escort people, for example to school and back home.
- Consider safeguarding during festivals, celebrations and other events where many people are gathered, and moving to / away from an area.
- Avoid leaving children with albinism under the care of somebody who you do not fully trust. Do not entrust them to somebody who has debts or criminal contacts.

Where needed, **mobilize community support** and companion systems and actively liaise with school authorities to demand protective action. Having many people that are aware, involved and alerted will go a long way towards keeping your family members safe.

Security guidelines for meetings

When you are organizing a meeting where one or several people with albinism will be attending, be aware of the risks for them to travel back and forth to the meeting.

- Research whether the area has seen any previous incidents of violence (against people with albinism) or whether criminal gangs are operating in the area.
- Consider safe means of transport.
- Set up a simple multi-person companion system. Remember that even two or more people may not be able to defend themselves against several armed men.
- Select and screen reliable accommodations where people can meet, eat and stay overnight without being targeted.
- Consider transportation, for example between the hotel and the meeting venue.
- Preemptively identify where a group of criminals may strike and provide adequate protection.
- Consider wise start and end times for the meetings so that people can be home or in a safe location before it gets dark.

For each larger meeting (e.g. a conference or multi-day workshop) **appoint an experienced person as Security Focal Person (SFP)** and task this person with concrete objectives to keep participants safe. Ensure the SFP is well equipped (working, charged phone with enough credit) and has an existing network in the area to swiftly raise an alert and mobilize supporting resources. Provide the name and contact number of the SFP to all participants and give a condensed security briefing for the specific location and event.

Security guidelines for managers

When you are the manager of a project, leader of a school or institution where people with albinism work, study or meet, you carry additional responsibilities to keep the people under your care safe. Below are several simple recommendations and easy / low cost actions to implement:

- Nominate a Security Focal Person within your team that has designated tasks to assess risks and vulnerabilities of people with albinism.
- Make Safety & Security a recurring theme at your management meetings where incidents, trends and patterns are discussed.
- Implement recommendations as soon as possible.
- Implement training for students, staff and specifically for guards and drivers as per this guideline.
- Equip students and other vulnerable staff with whistles on a cord.
- Organize **assistive devices** such as *photochoromatic* glasses for people with albinism to improve their vision for surveillance of their environment. If these are unavailable or too expensive, sunglasses as well as correction of refractive error using simple glasses can yield some improvement of vision.
- **Demand that guards and drivers take their duties seriously** and proactively patrol and monitor the streets, gate and compound.
- Set up an alert system through which you can swiftly channel information about possible risks. Urge people to report all incidents, 'near misses' and suspicions so that possible patterns can be monitored.
- Set up and communicate a **designated reporting channel** for incidents.
- Screen the vulnerabilities of transport and determine safe routes and routines for students and staff.
- **Implement companion systems** and where needed arrange formal, safe transport.
- **Keep rigid attendance systems** so you know at all times who has and has not arrived. Take swift action when somebody is late or unaccounted for.
- When you have a boarding facility where students or staff stay overnight, carefully assess the risks to people with albinism and take action according to these August 2016, Malawi
 - albinism and take action according to these guidelines. In particular consider the fencing of the premises and ensure that proper locks are on every entry way.
- Prepare for a possible crisis situation by having names, photographs, next of kin and addresses of all staff and students.
 Store data confidentially to avoid misuse!

In a field setting just outside Blantyre, three attempts at abducting a 6 year old girl with albinism took place when men tried to entice her into their car. It was foiled by those directly around her responding swiftly. Security Guideline for People with Albinism

- **Consider doing a Crisis Management simulation exercise** with your team or seek support to implement a security and crisis management training.
- Ensure you have an up-to-date list of Emergency Contacts so you can swiftly reach out to police, authorities, community and religious leaders as well as (local) media such as radio stations.

Immediate incident management

Naturally it is best to focus the majority of time, energy and resources on training and prevention of incidents. **Much can be done indeed to avoid incidents.** However incidents will happen and, if they do, your preparedness and quick reaction could literally save lives. Experience has taught that well thought out and rehearsed incident responses, increases the chances for a victim to come out of a dangerous situation unharmed.

With regard to incident management, the early stage is the most crucial **phase.** When we look at the most common and severe scenario – the abduction of a person with albinism – we have to be realistic and face the facts however gruesome the topic.

Criminals who abduct a person with albinism generally have two motives; sexual and/or financial. A kidnapped girl or woman (sometimes also boys and men)

may be forced into sexual intercourse and contract HIV or become pregnant.

A kidnapped person will be taken to a quiet location shortly after the abduction where he or she is killed or maimed with the aim to sell the body parts. The longer perpetrators wait, the higher their chance of being discovered. **Because the motive for kidnapping people with albinism is different, there is no time to waste.** There will be no contact attempt or a period where negotiations take place regarding a ransom.

Malawi, 2013

In one village (where a step father was the abductor of a young girl with albinism) the community had spent six hours searching for herand not found her as she had escaped and hidden in a pit. A courageous story of both assertiveness by a young girl and of a whole community pulling together to respond.

Occasionally a criminal community member (or somebody with debts) may take somebody with the aim of selling the person to a gang offering cash money for a living victim.

The (few) successful cases where abducted people have been found alive and freed, generally had one thing in common: an entire community was alerted and rallied into immediate action to search for a victim. With hundreds of people looking and searching, community elders condemning the incident and religious

leaders urging their followers to assist, a relatively big area can be covered, a victim found and perpetrators apprehended.

Unfortunately, apart from strong preventative action, we have very few options to end this crisis positively.

You must act immediately to solicit a response from the community:

- 1. We need the community leaders (local MPs, chiefs) to strongly condemn what has happened.
- 2. We must urge them to mobilize community members to help search in groups, each covering a designated area.

The below flowchart will help you assess a situation, take decisions and mobilize resources to find a missing person.

Getting the community aspect right is paramount. This can only be accomplished through pre-established and well-rehearsed contingency plans. Precious time will be lost if incident managers struggle to find up-to-date contact data. Response will be slow when people have not bothered to keep their contacts in the community current, and do not know who among the authorities to reach out to.

Your team, project or school leadership must invest in buy-in from the community, chiefs and religious leaders and have pre-established and maintained networks of emergency contacts. The greater the **acceptance** of your mandate, the more effective your ability to mobilize support.



Immediate action

You must therefore act **immediately** to solicit a response from the community leading to a massive outcry.

Flow diagram – initial handling of an alert or incident

| Ar | n alert comes in (in <u>whatever form) th</u> | nat a | an incident (e.g. disappearance, kidnap, |
|-----|--|-------|---|
| | | | on with albinism has occurred. |
| | | | |
| | ure of the incident | | Nature of the incident |
| | rious) | | (non-serious) |
| | ion: | | Action: |
| 1 | Establish the facts; who, where, what, when? | | 1 Ensure the wellbeing of the involved person. |
| 2 | Verify the facts with the original source of information. | | 2 Draw basic lessons (what could be done differently, is there a trend or pattern?) |
| 3 | Assess the incident: if false or low threat. | | 3 Share the lessons with stakeholders and implement without delay. |
| 4 | Assess the incident: if true and if people are at risk immediately: | | |
| Inc | ident management | | Good outcome scenario |
| | ion: | | Action: |
| 1 | Send a team to the incident location to establish facts and search for / support the victim. | • | 1 When the missing/abducted person is found, provide care and psychosocial support to the victim (see below). |
| 2 | Form a Crisis Management Team to coordinate next steps and set contingency plans in motion. | | 2 Arrange psycho-social assistance to the family / classmates of the victim (see below). |
| 3 | Raise an alert and enhance security measures at facility and during transport. | | 3 Assess the incident, learn from how it was handled and observe risks and trends or patterns. |
| 5 | Verify the wellbeing of all other (vulnerable) persons. | | 4 Implement recommendations without delay. |
| 5 | Contact key authorities and request urgent support. | | 5 Thank all those who supported you and request ongoing interaction. |
| 6 | Contact local community leaders and request support. VITAL & URGENT | | 6 Reinforce alert networks and people's knowledge on incident prevention. |
| 7 | Contact local religious leaders and request support. VITAL & URGENT | | |
| 8 | Contact family / next of kin to establish facts and mobilize resources. | | |
| 9 | Use (social) media to raise an alert and request support. | | |
| 10 | Assess the incident, learn from how it was handled, observe risks and trends and implement recommendations. | | |
| | | | |

Psychosocial Support

It is important that a person who has undergone a distressing or traumatic experience is able to **receive appropriate support** from their family and community, and if necessary, from professionals focused on mental wellbeing. Some simple principles can help to ensure that people benefit from available support mechanisms and avoid being further harmed by attempts to help them.

| LOOK | » Check for safety. » Check for people with obvious urgent basic needs. » Check for people with serious distress reactions. | Å |
|--------|--|--------|
| LISTEN | » Approach people who may need support. » Ask about people's needs and concerns. » Listen to people, and help them to feel calm. | R T |
| LINK | » Help people address basic needs and access services. » Help people cope with problems. » Give information. » Connect people with loved ones and social support. | ŘŘ |

Basic principles of Psychological First Aid¹

Look: Make sure that the person is out of danger and that their basic needs are addressed. Are they safe? Do they need food or clothing? Are they in an environment where they feel comfortable and secure?

People who are clearly very distressed, emotional or unable to communicate soon after an incident need to be given time to recover. If they are severely distressed after a long period, it may be necessary to refer them to specialists. *No-one should ever be forced to recall or 'debrief' if they do not want to talk about their experience.* This can be distressing and is not therapeutic unless the person wants to do so.

¹ *Psychological first aid: Guide for field workers* (World Health Organization, War Trauma Foundation, World Vision International, 2011). Used with permission.

Listen: The most important thing that can be done to support a person who has been traumatized is to show that you are available for them, and concerned for their welfare. Show empathy and a willingness to give them time to listen. Ideally, friends and family can offer this support.

If you are not known to the person, introduce yourself and ask how they are and if they want to talk (if possible in a quiet and private area). Ask if they have any particular needs or concerns. Never insist that they talk, or ask overly intrusive questions. If they are anxious or distressed, calm them down and reassure them that they are safe (if this is true). Speak quietly and calmly, maintain eye contact.

Link: Help people to address their concerns and access the basic needs they say they have. Connect them to family and friends who can help, and link them to services that can help them for the long-term, either practical or in terms of further physical or mental health care.

In general, it is important that while following these safety recommendations, people with albinism are able to be included in the usual activities of communities. These recommendations should help people to feel safe rather than live in fear. They are not to blame for the situation, and emphasis should be put on changing the abusive behavior of others in the community.

When communicating risks to children in particular, it can be helpful to;

- give them more time to speak and absorb information.
- share basic information in a way they can understand and give them a chance to ask questions. This includes discussing when an incident has occurred or when there are rumors in the community/school.
- make sure they know that they are not to blame for the situation.
- be patient if they display behaviors like wetting the bed, which will resolve when over the crisis.
- not separate them from loved ones, and encourage normal routines in a familiar environment.

Informing authorities

There may be national contacts either in state or civil society who can be informed, with the person's permission, to help track incidents. The more incidents that are reported centrally, the better trends and patterns can be assessed, authorities informed, action taken and perpetrators brought to justice.

In addition to the above steps, when you experience an incident regarding a person with albinism, we strongly recommend that you **send an alert** to the UN's **Independent Expert on the enjoyment of human rights by persons with albinism** via: <u>albinism@ohchr.org</u> or use Facebook/Twitter/Instagram: @unalbinism or use Facebook: "UN Albinism..."

Working with the media

During a crisis event, the role of the media is crucial. Wise and coordinated involvement of the (local) media can bring an incident to a positive outcome. Unwise involvement however could be detrimental to the fate of the victim and promote more attacks.

Media messages that strongly condemn an attack and disempower the local erroneous beliefs about the magical power of body parts are extremely beneficial. Incrementally we may see community awareness grow on this topic. During a current incident such news articles enhance positive anger and desire among communities to help rid the world of this evil. We should work with the local media to avoid speculations and correct wrongs. The media (e.g. local radio) could mobilize local groups and communities to help find a victim while s/he may still be alive and in the area. Urge media to **never mention the value of body parts** of persons with albinism as it may inadvertently spur attacks.

It is possible that in your role as Security Focal Person or Manager of a project, the media contacts you for a response or to get additional information. **We advise you to be careful with what you release. Best is to work with formal media statements** (where feasible), scrutinized carefully by a team working on the incident.

Always avoid any speculation or release personal details about a victim or his/her family to the media. You can always safely confirm that an incident has taken place and that you **urge all community members to look out for a victim with a generic description.** Use the opportunity, when contacted by the media, to correct wrong beliefs and superstition around people with albinism.

Using social media and technology

In this day and age of social media, Facebook postings and Twitter messages will often be the first place where an incident gets reported. Traditional media often pick up their first reports from such channels and start inquiring and reporting.

When your organization has an active social media presence, you could use these platforms to swiftly send out an alert for a missing person to many followers. Ask them to help search, keep an eye out and report to a given address with relevant information. Modern technology like WhatsApp groups are ideal technical platforms for swiftly sharing information within a group. In Malawi people with albinism have formed dedicated groups on WhatsApp where they share useful information.

Research on albinism

When doing research or interviews on albinism, ensure full data protection of those you interview so that people with albinism cannot be traced.

Learning from the crisis

Irrespective of the crisis outcome, it is advisable to **evaluate the handling of each crisis** after an incident. This will improve your organizations' contingency planning and professionalize how future incidents are handled. It may even help you avoid another incident and share useful lessons learnt with other organizations.

Take time to honestly evaluate what went well and what did not go so well.

- Were protocols set in place to help protect people with albinism followed?
- How was the flow of communication?
- What was most successful?
- Were you able to mobilize your resources quick enough?

From there, come up with tangible recommendations and do not delay implementation. Also ensure that you further train and instruct your staff when protocols and routines were not (sufficiently) followed.

We are deeply concerned about the plight of people with albinism and the terrible violence with which they are confronted. We sincerely hope that this publication will help deter further attacks and safeguard precious individuals.

Safety and security for people with albinism is culturally contextual. It is worth **distinguishing between cultures** where people with albinism are discriminated against or abused generally, and those where there is a specific risk of abduction. We don't want to imply that these risks are universal.

Especially in **conflict and disaster zones** where people are fleeing for their lives with the little they can carry, people with albinism are extra vulnerable. The exposure of people with disabilities and especially people with albinism should be carefully considered, planned and mitigated in **Disaster Risk Reduction** and Relief Programmes.



Disclaimer of liability: "CBM, Christoffel-Blindenmission and Christian Blind Mission e.V. shall not be held liable for any improper or incorrect use of the information described above and assumes no responsibility for anyone's use of the information".



More information

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CBM is an international Christian development organisation, committed to improving the quality of life of people with disabilities in the poorest communities of the world.