

Albinism in Malawi project newsletter January 2013

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AIMZ: Albinism in Malawi & Zambia

Published version deposited in CURVE April 2013

Original citation & hyperlink:

Lund, P. (Ed.). (2013). Albinism in Malawi project newsletter January 2013. AIMZ: Albinism in Malawi and Zambia.

Additional note:

The two booklets referred to in this newsletter are also available from Curve:

[Albinism in Malawi: information for teachers and parents](#)

[Albinism in Malawi: information for children](#)

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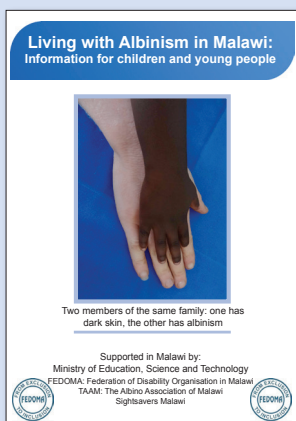
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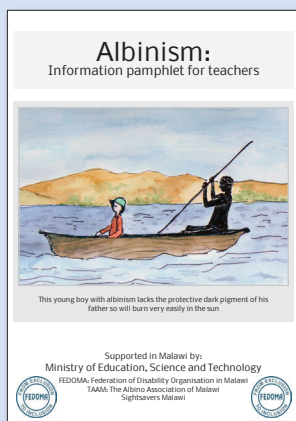
Albinism in Malawi

Information on albinism in Malawi

These booklets give details of genetic, health, social and educational issues around albinism



This booklet explains that those with albinism have no dark pigment in their hair, skin and eyes. In other ways they are just like anyone else.



This booklet focuses on simple and low-cost ways in which teachers can assist children with albinism in mainstream classrooms.

To receive copies of these booklets (also available in Chichewa) contact Dr Patricia Lund at p.lund@coventry.ac.uk or Boniface Massah of The Albino Association of Malawi at bonmassah@gmail.com or by cell phone on (265) 0999 544 2346 or 0881 006 474

Development of these information pamphlets was co-sponsored by Coventry University (UK), The Commonwealth Secretariat (UK), Sightsavers (Malawi) and University of Birmingham (UK). These pamphlets may be used free of charge for any non-commercial purpose providing that the above acknowledgement of the sponsors is given.



Answering questions on albinism

Extracts from the children's booklet: **Vision**

Is my eyesight different from others?

Yes, because your eyes lack pigment this changes the structure of your eyes. They 'wobble' from side to side which makes it difficult to see detail and means your eyes are very sensitive to bright light.

This booklet addressed myths about the eyesight of those with albinism

Will my eyesight get worse as I get older?

No, your eyesight will change as you get older, but you will not lose your sight.

Will I go blind because I have albinism?

No, albinism causes low vision, not blindness.

Should I learn Braille?

No. If you can see when you hold the book or object close to your eyes you do not need to be taught Braille.

Most people with albinism have sufficient vision to read without Braille.



The Chimodzi family. Virginia has albinism whereas her mother and aunt are black.

When Virginia started school she did not realise her friends could all see the board while she could not. She asked for help from her teachers and now she is a teacher herself.

Extracts from the children's booklet: **Sun Protection**

The booklet also includes hints on sun protection

How can I protect myself from the sun?

- Wear a wide brimmed hat every day to protect your skin and eyes
- Wear long sleeved shirts and long trousers or skirts and sunglasses
- Choose dark, tightly woven material such as denim to give good protection from the sun
- When buying clothes hold them up to the light and choose ones you cannot see through
- Seek shade or remain indoors whenever possible, especially in the middle of the day, when your shadow is longer than you are.



...and answers questions about sun exposure

Will I go dark if I stay in the sun?

No. Your skin will go red, it will burn, blister and peel.

This can be painful so avoid the sun as much as you can.

If you have wounds on your skin that do not heal, ask to go to the clinic or hospital.

When should I protect my skin from the sun?

Every day! All year round! Even on cloudy days.

Damaging UVA rays reflect off water, sand and concrete and pass through glass.

This means your skin can burn if you are out on a river or lake, even if you are wearing a hat.

Those with albinism have the same potential and abilities as others



These drawings were done by Blessings, a young boy with albinism who has a talent for drawing.



Teaching Tips

The teacher's booklet gives a list of hints on how to adapt their teaching style to accommodate learners with albinism without the need for additional resources.



Find the best environment in the classroom (usually in the centre at the front, close to the board and away from direct light).



'I don't see properly so sometimes my friends write notes for me and help me read the notes.'

Everyone has the right to a good education

New project using radio and mobile phone messaging to highlight the lives of people with albinism: their challenges and success stories

The project is funded by Sightsavers, through their strategic partnership arrangement with the UK's Department for International Development (DFID). It will enable pupils with albinism to lead better and more productive lives by promoting their educational inclusion and enhancing their acceptance within local mainstream schools, with appropriate support from specialist teachers in visual impairment. This project will use radio and mobile phones to promote these inclusive educational initiatives.

Teacher training: workshops and radio training programme

A key aspect of this project will be face-to-face workshops for lecturers at Teacher Training Colleges, to empower them with the knowledge to include albinism as a topic in their Special Needs Education training for all teachers.

A national radio programme on albinism will help inform all teachers, as well as members of the public.

The Project team

Dr Patricia Lund

Project Manager

Faculty of Health and Life Sciences, Coventry University, UK
p.lund@coventry.ac.uk

“Over the past 20 years I have been privileged to meet many families living with albinism in southern Africa as well as teachers in both mainstream and specialist Resource Centres in Malawi. I look forward to working on this project to promote education on albinism with colleagues in Malawi, Zambia and here in the UK.”



Dr Gareth Dart

Co-project manager

Institute of Education,
University of Worcester, UK
g.dart@worc.ac.uk



“Having spent many happy years in teacher education in Botswana and Zambia I am very excited to be involved in this project. The way that colleagues with albinism in Botswana overcame so many challenges has been a great inspiration to me and I am sure that this project can support many other children with albinism to lead fulfilling and successful lives.”

Dr Paul Lynch

Expert in Visual
Impairment

Department of Disability,
Inclusion and Special
Needs (DISN) at the
University of Birmingham, U.K.
p.lynch@bham.ac.uk



“I am particularly interested in the development and impact of interventions that seek to increase the educational participation of children and young people with visual impairment in mainstream schools. I have a strong interest in using participatory action research approaches when carrying out research in sub-Saharan Africa.”

Boniface Massah,

Project officer (Malawi)

District Rehabilitation Officer,
MACOHA Balaka
bonmassah@gmail.com



“I am proud to be a person with albinism and I have accepted my condition as a beautiful and unique creation of God, thus I have developed a positive attitude toward my life. I cherish the love from my parents, relatives and friends that has seen me penetrating through a society full of myths on albinism and negative attitudes towards people with albinism.”

Anderson Fumulani,

Media consultant
(Malawi)

Centre for Media Advocacy
and Interaction Limited,
Blantyre
afumus@africa-online.net



“People with albinism are just like any of you and me. They feel, they love, they want love. I have many friends with albinism. We share lots of quality experiences.”

Partners in Malawi include

Alick Chavuta

Malawi Council for the
Handicapped (MACOHA)

The team will work closely with community rehabilitation officers to identify families affected by albinism and include them in this project.

Ian Simbota

Actor, storywriter and advocate for people with albinism

“After 25 years of my life in this world I stand to tell the story of my life both negative & positive, showing how hard is it to live in Malawi with a disability.”

Dr Elizabeth Tikondwe Kamchedzera

Faculty of Education, Chancellor College, Zomba, Malawi

We will be working with Dr Kamchedzera to integrate albinism as a topic in disability training workshops and curricula. We will develop in depth case studies of families affected by albinism, to demonstrate the challenges they face.

Abigail Dzimadzi

Trustee of The Albino Association of Malawi



“Making sure children with albinism have the same educational opportunities as their normally pigmented friends is so important, because apart from the skin colour, children with albinism are just as curious, talented and have the same potential of achievement. This project by Coventry University will help the children with albinism in Malawi get a voice and as a trustee for the Association of Albinism in Malawi, I am proud to be a partner.”

Fidelis Chasukwa Mgowa

Catholic Relief Services



“Humanity is like a necklace, if one bead falls apart, we lose the necklace. Let us promote educational inclusion of children and young people with albinism in Malawi.”

In 2013 the team aim to establish new collaborations and partnerships within the community.

Working with The Albino Association of Malawi (TAAM)

Message from the Chair of TAAM:

“Like any person with disability, we people with albinism experience the same stigma and discrimination. It's high time we look beyond our skin colour, develop our self-esteem and realize that we are people created in God's image with a common purpose. The community must love us, not treat us as strangers. We can love, dance, smile, get angry and enjoy a sexual life because we are human beings. We need not always be reminded that we look different-white skin- as it pains and makes us feel out of place once we realise that everyone's eyes are looking at us.”



Young girl with albinism in Malawi

Contact us!

Dr Patricia Lund in the UK
p.lund@coventry.ac.uk

Boniface Massah in Malawi
bonmassah@gmail.com
Tel 0999 5442 346 or 0881 006 474

Anderson Fumulani in Malawi
afumus@africa-online.net
Tel 0888 954 854

Join us!

Do you have an interest in, or experience of albinism?

Would you like to write a drama, a song or talk about your experiences of albinism?

Contact us!