



ALBINISM

**CELEBRATING DIFFERENCES
UNLOCKING POTENTIAL**

Appreciation Letters

Dear Dr. Prabha Choksey,

This is an appreciation note from a sincere heart of a lady expressing how she feels on what you did to her dying eye sight. For long I stayed in darkness not knowing that there will be a day that I would walk without stress and straining. My world of darkness grew bright since that day I got a new pair of glasses prescribed by you doctor! Since then I see things from a distance and bright just like the normal eye, no more bumping into people and stones not forgetting matatus and road crossing tips.



May the lord God almighty bless you both in health, wealth and in spirit for all the love and affection you devoted to this "forgotten species" (people with Albinism) May he grant you all your wishes for he has all the power and might. Be Strong in your mission for we depend on you for a strong healthy and Educated Albinism Association.

Kuddos Doctor Choksey!
Yours Faithfully
Edna Tuti

Dear Dr. Prabha Choksey

Mother Sweet mother
Mother of mercy
Mother of good heart
Mother of love
That's who you are



Words are not enough to say who you really are
Words are not enough to thank you for what you did
Words are not enough to explain the sacrifices you made to make me happy
Words are not enough to express my gratitude
But this remains an unpayable debt

It's not that you know me
It's not that we are related
It's not that you knew my background
But you decided to educate, take care of my health and made me enjoy fullness of life
This remains an unpayable debt

You may not know but you brought back to life dead hope
You may not know but you brought strength to a devastated desperate heart

You may not know but through you a test was transformed to a testimony

You may not know but by helping one person, you've changed a group's life
But this remains an unpayable debt.

By Beatrice Wanja Ngugi

Dear Dr. Prabha Choksey,

Mother of good hope, many have seen light shine
Through you we have way to follow
From the darkness you brought us
And in the light you let us shine
Brave mother!! Reward awaits you



Children of different background we are,
Children of different mothers we came
Together you brought us and made us one
Your love you divided among us
Brave mother!!! Reward awaits you

In the society of discrimination and hatred
You brought equality and love among us
In world of darkness you became our light
Hopeless we were, but you became our hope
Sweet mother we salute you

With tears full in our eyes
You wiped us with care
With a hug, balanced we became
You opened your hands wide and received us
Kind hearted mother reward awaits you

Expensive glasses you gave us
With no charges mother
You made our world beautiful
For an albino child to live
Smiles we can afford
Because of you mother
In heaven, reward awaits you..Mum.

What reward can we give you in return?
What gift can we give you in return?
From deep our hearts mother we say thanks
An Albino person can acknowledge that
You have made the world beautiful to live
May God see you through and bless your work
Bravo mother Bravo!

By Doreen Gakii

Introduction

Dr. Choksey Albinism foundation is a **charitable trust** established in Kenya with the objective of reaching out to and assisting people specially children with Albinism.

The purpose of its **Help Ever-Hurt Never** initiatives is to bring together people of goodwill interested in joining hands with the organization to improve the quality of life of people with Albinism.



Dr. Prabha Choksey the founder is an Ophthalmologist with over 40 years of experience in the subject. In 2007 she realized the urgent need to reach out to children with Albinism many of whom were single parent children belonging to low socio economic background and who were forced to attend schools for the visually impaired at Primary and Secondary level without addressing their **low vision needs and challenges**. Since 2008 she has been offering Ophthalmic services free of cost to all people with Albinism and providing them with free prescription photochromatic glasses and has reached over 1000 people. She is the proud recipient of

- **Award of Excellence from Ophthalmic society of East Africa** for outstanding contribution to Eye Care in East Africa in 2007.
- **Bharat Jyoti Award** (27/3/2012 New Delhi India) **Gem of India** (20/6/2012 Bangkok Thailand) from **India International Friendship Society**.
- **Award and Honor Moran of the order of the Burning Spear** (MBS) by H.E President of Kenya Mr. Mwai Kibaki on 12th Dec 2012. This honor was bestowed upon her in recognition of outstanding and distinguished services rendered to the Nation in the field of Ophthalmology and for her selfless and generous commitment to help children with Albinism.
- **Bari Bari Prize** 2016–2017
Installed in the memory of Ambassador Yusuf Mohamed Ismail Bari Bari of the UN who was a fighter for Human Rights of persons with Albinism, this annual award recognizes Individuals who make a difference in the lives of people with Albinism worldwide.
- **Award of Excellence from Kenya Women and Children wellness Centre (KWCWC)** was given to Dr. Prabha Choksey during International Women's Day Celebrations in Kenya on 8th March 2017 for distinguished services rendered to people living with Albinism.
- **Jacob's well Award** for being a woman who has helped in uplifting others on 17th March 2018.
- **Kenbharti's Women Achievers Award** on 11/8/2018 for outstanding contribution towards society and services above self.
- **Golden Heart Award 1/9/2018** for meritorious services to the less privileged in the society by Shree Navnat Vanik Mahajan community.

Albinism



Albinism is a genetic condition present from birth and is characterized by lack of pigment called Melanin in the **Skin, Hair and the Eyes**.

Melanin is a photoprotective pigment that plays a major role in absorbing Ultra Violet radiation from the sun.

Lack of pigment in the skin and hair makes the Persons with Albinism appear light with blond hair. Lack of pigment in the Eyes makes them live with severe visual challenges and it is the major cause of disability and morbidity in them.

Albinism And The Skin

Absence of the pigment Melanin makes the skin of the persons with Albinism to be extremely sensitive to the Ultraviolet radiation of the sun.

Exposure to the sun causes their skin to develop 'Blisters' and 'Cracks' leading to itching, pain and general discomfort. Prolonged exposure to direct sunlight without skin protection can lead to development of Skin Cancer.

Cancer in Albinism is preventable through avoiding direct exposure to sunlight and using sunscreen lotions with High Sun Protection Factor SPF 30 and above.



Albinism And The Eyes



Lack of pigment Melanin in the eyes leads to **visual challenges and reduced vision** whose degree varies from person to person.

They could be **Myopic** (short sighted) **Hypermetropic** (long sighted) or have **Astigmatism** which causes the images to appear unfocused.

In the past the focus of the world was on the skin of persons with Albinism overlooking the fact **that involvement of the eyes is the real disability and challenge in Albinism**. What differentiates the people with Albinism with the fair people of Caucasian race are the eyes.

Early diagnosis of the underlying Refractive error by an Ophthalmologist and provision of appropriate glasses with Photochromatic lenses and other visual aids before the age of 7 years can help improve and preserve sight.

In addition to remarkable improvement in vision **Photochromatic glasses** help the persons with Albinism to keep their eyes open and not squint in sunlight and prevent development of Amblyopia (low vision) in their later life.



Persons with Albinism also have **red reflex in their pupils**, their irises allow too much light to enter their eyes leading to '**photophobia**' which literally means '**fear of light**'. They also have constant involuntary pendular movements of the eyes called '**Nystagmus**' which results in problems in co-ordination and fixing of the eyes on objects.

It is important to understand that in spite of serious visual challenges and contrary to the popular myths and misconceptions person with Albinism are not blind.

Education In Albinism



“ Education is the most powerful weapon
you can use to change the world
Nelson Mandela ”

There is a strong link between the child's sight and their learning capabilities, performance in school and in their education. Lack of melanin in the eyes leads to poor vision in all persons with Albinism **but they are not blind and** have adequate vision to study in normal Schools and in print.

They however require assistance with

- Large Type Text
- High contrast written material.
- Computers with large character display
- Copies of teachers notes for close up reading (lack of pigment in the eyes is responsible for inability to read small print at normal distance)
- Permission to sit in the front of the class
- At least 30 minutes extra time during examination.



Goldalyn Kakuya Tanga a child with Albinism created history in Kenya by emerging the best performing student at Kenya Certificate of Primary Education (K.C.P.E) in 2017.

Scoring 455 out of 500 marks and beating 993,718 candidates Countrywide proved to the world that disability is never inability. Through her success she has set very high standards in academic excellence for future generations of Children with Albinism in regular schools in Kenya.

Albinism And Life Span



81 Years Old Man with Albinism

Albinism is associated with normal life span. It is an **autosomal recessive condition** meaning the individual inherits the gene of Albinism from both parents.

A person with Albinism can marry someone who is not a carrier of the gene and raise families and have children with normal pigmentation. **Genetic counseling is important when there is Albinism in the family.**

Challenges Of Living With Albinism In Africa



The condition of Albinism and its genetic nature is totally misunderstood in the world. The birth of an Albino child in an **African** family is usually considered as a 'curse' to the family.

In many parts of Africa people usually children with Albinism are hunted down as if they are wild animals. Many continue to be slaughtered by witchcraft practitioners in the misplaced belief that their bones and body parts have magical powers of curing afflictions such as Cancer and AIDS. A very high price is put on their bones and body parts.

Many women are thrown out of their matrimonial homes on the birth of an Albino child on suspicions that the child was fathered by a white man. There is a very high percentage of single parent children and children living with grandparents in Africa.

Ignorance, poverty and Tropical climate contribute greatly to children suffering serious challenges in life.

Africa's most precious and beautiful children continue to live a life of fear and ridicule devoid of parental love and acceptance by the society.

Dr. Choksey Albinism Foundation

Dr. Choksey Albinism Foundation is a Charitable Trust in Kenya that is bringing hope and helping people with Albinism celebrate their differences and unlock their potential.

Motto - Help Ever Hurt Never

Belief - Service to Humanity is service to God

Vision - A society in which persons with Albinism are fully integrated appreciated and empowered to realize their full potential.

Logo



2 Hands represent the helping hands of Dr. Choksey Albinism Foundation.

2 Black figures represent the parents and families of person with Albinism.

1 white figure in the center represents a happy Albino child.

Map of Africa is the 'black' world where 'white' Children with Albinism live.

Dr. Choksey Albinism Foundation Is Transforming Lives Of Persons With Albinism Through Gift Of Sight

The foundation is addressing the issues of visual challenge in people with Albinism by providing free ophthalmic services and free prescription photochromatic glasses to all persons with Albinism and has reached over 1000 people.



Through observations and studies the **foundation has established the fact that with prescription photochromatic glasses over 95% of people with Albinism do not come in the bracket of legal blindness. Though visually challenged all children with Albinism have adequate sight to study in normal schools and in print.**



Dr. Choksey Albinism Foundation is striving to ensure that all children with Albinism get quality education in regular schools.

The foundation runs a **School Sponsorship Programme** for Children with albinism from Low Socio Economic background, Orphans, Single Parent Children and children living with grandparents in Kenya. The foundation supports

the education of over 80 Albino Children through support from various private Institutions in Kenya annually.

Raise awareness about Albinism and to bring the attention of the world to the plight of people living with Albinism in Africa where **ignorance** about the condition and **poverty** contribute greatly to their suffering great challenges.

Facilitating access to sunscreen lotion with high sun protection factor SPF 30 and above.

Help Ever-Hurt Never initiative of Dr. Choksey Albinism Foundation reaches out to assist financially young people in higher education in Colleges and Universities, entrepreneurs and those who need support in developing life skills such as Music, Art, IT etc.

It will be the endeavor of Dr. Choksey Albinism Foundation through networking, creating role models and education to create an environment in Kenya where all children and adults with Albinism live a life of **Dignity and Honor.**

Dr. Choksey Albinism Foundation Demystifying The Myths About Albinism In Africa

Myth 1

Birth of an Albino child is a punishment from God and is a curse to the family.

Albinism is a genetic condition that is passed on from both parents and is present from birth. Since the gene of albinism is a recessive gene both

parents do not themselves have any signs and symptoms of Albinism. Just as Albinism is seen in nature, in animals, plants and birds it is seen in human beings. Children with Albinism are a blessing to the family and not a curse.

Albinism in Nature



Myth 2

Body parts of persons with Albinism, their bones and potions made from the skin make charms that can make people rich and successful.

Children with Albinism are the most precious, extremely beautiful and extremely intelligent Children of Africa. This myth in the past led to Albino children growing up with fear, ridicule, low self-esteem, stigmatized and shunned by the society. Leaders and decision makers of the world must give severe punishment to those who kill and those who purchase the body parts of Albino children.

Killings must stop.

Myth 3

Persons with Albinism die early. Their life span is not more than 35 years.

*Persons with Albinism have a normal life span.
If persons with Albinism marry someone who is not*

a carrier of the gene they can raise normal families and have children with normal pigmentation.

Myth 4

Persons with Albinism have magical powers of curing people of terminal diseases such as Cancer and AIDS.

Like normal people persons with Albinism can themselves suffer from cancer and AIDS. If they had the magical powers they could have cured themselves.

Myth 5

If a person with Albinism is exposed to sun for a long time he or she will get pigmented skin.

*Due to lack of pigment Melanin the skin of persons with Albinism is extremely sensitive to sunlight. Prolonged exposure to direct sunlight can lead to skin cancer. **Since it is a genetic condition if a person is born with Albinism they will die with Albinism;** they can never get pigmentation with exposure to sun or any other medical treatment.*

Myth 6

All children with Albinism are blind and must study in blind schools or schools for the visually impaired.

*For generations the focus of the world was on the **skin** of a person with Albinism overlooking the fact that **involvement of the eyes is the primary disability, morbidity and challenge** in persons with Albinism.*

A decade ago 70-80% of Albino children in Kenya were enrolled in Blind Schools, many were taught

in braille violating the basic human rights of Albino children.

As an Ophthalmologist of over 4 decades the founder of **Dr. Choksey Albinism Foundation**. **Dr. Prabha Choksey** who has been offering **free ophthalmic services** and providing **free prescription photochromatic glasses** to all people with Albinism since 2008 and having reached over **1000** people has established the fact that **with prescription glasses over 95% of persons with Albinism do not fall in the bracket of legal blindness and can study in print in regular Schools.**

Myth7

A child is born with Albinism when the mother is unfaithful in marriage and that the child was fathered by a person of the white race.

*This Myth has led to a large number of broken families **single parent albino children** and children brought up by **grandparents** in Africa.*

Diagnosis of Albinism at birth is crucial for the survival of an Albino child and the family.

Myth 8

If a pregnant woman sees a person with Albinism she should spit on the floor 3 times otherwise the child she is carrying will be born with Albinism.

This Myth is due to ignorance and misunderstanding about the genetic nature of Albinism and has no scientific basis.

Myth 9

Albinos never die, they just disappear. In many parts of Africa persons with Albinism are referred to

as **Zeru Zeru** which literally means a **Ghost**.

This myth has no basis as persons with Albinism are normal human beings with normal life span and also die like normal people.

Myth 10

Albinism is contagious and can spread from one person to another through body contact or even with handshake.

This myth has led many persons with Albinism lead a solitary life without many friends and low self-esteem. This myth too is due to the ignorance about the genetic nature of the condition.

Dr. Prabha Choksey's Recommendations On Bringing Up A Child With Albinism

Diagnosis of Albinism at birth is crucial for the survival of an Albino Child. Doctors and midwives conducting the delivery must be aware of the condition and should be able to make the diagnosis by looking at the eyes. **Absence of pigment melanin in the eyes is associated with light coloured irises and a red reflex in pupillary area**, which can easily differentiate between an Albino Child and that of a white race child.

Counselling the parents and the family about the genetic nature of Albinism is an important step at birth specially in Africa. The parents must be made aware of the fact that **both of them** are carriers of the gene of Albinism and could have more Children

with Albinism in future.

In early childhood, bringing up the Albino child as **a normal child** with parental love and acceptance by the extended family and the society is an important milestone in the lives of Albino Children.

Albinism and skin

The parents and the family must be made aware of the harmful effects of exposure to direct sunlight on the skin of the Albino Children. In early childhood the skin can be protected by keeping the child indoors during the day, using protective clothing such as hats and full sleeves shirts carrying an **Umbrella** when the child is taken out in the Sun. Using Sunscreen lotions with high **Sun** protection factor SPF 30 and above are recommended.

Albinism and the Eyes

An Albino Child must be examined by an Ophthalmologist between **3 to 6 years of age**. **Prescription Photochromatic glasses must be provided before the age of 7 years to improve and preserve sight.**

Education in Braille for children with albinism must be totally & permanently stopped in the world.

Youth & Career Choices In Albinism

Most suitable professions for people with Albinism are those that are pursued Indoors such as **Teaching, Law, IT Consultants, Banking, Telephone Operating, Management, Physiotherapy, Engineering, Medicine, History and Politics.**

Careers that must be avoided are Agriculture, Farming, Police, Army, Salesman etc which involve being outdoors.

Albinism — Relationship and Marriage

Albinism can occur only if both Parents carry the gene of Albinism.

Persons with Albinism can marry someone who is not a carrier of the gene and can have children with normal pigmentation and raise wonderful families.

Genetic counseling is important when there is Albinism in the family.

Life of Dignity and honor

*“ The Philosophy of the School rooms
in one generation will be the Philosophy
of the Government in the next.
Abraham Lincoln ”*

Time has come for the world to unite to ensure that Children with Albinism are fully **Integrated, Appreciated and Empowered** to realize their full potential and lead a life of **dignity and honor** as adults.

Appreciation Letters

Dear Dr. Prabha Choksey

"They say everyone has an angel watching over them and I know I am right to say you are an Angel on earth sent by God to people with Albinism. In you we find a mother, friend and a mentor.

Every person who passes through your office comes out a different person with lots of energy to face a bright future.

Thank you for your continuing support. As you always say even one person can move mountains and yes our lives have changed for the

better because of you
Dr. Choksey"

Josephine Wangechi



Dear Dr. Prabha Choksey

"I thank God for giving me this opportunity to write to you.

The world doesn't need more mountains to climb more rivers to cross or more stars to shine. What the world needs is just more people like you. I pray that God will continue blessing you and your family for touching my life and also the lives of other persons living with Albinism.

Doctor I have only one promise to make I will always pray for you".

Ann Mbu



Dear Dr. Prabha Choksey

"I really hope you are well because God knows you should be well. You deserve happiness in its fullness as all you have been doing for the last ten years is to give happiness to people with Albinism.

I will never forget your reception to me in late October 2016. Never had I felt so warmly welcomed by anyone in my life. It was like a mother's reception of a long lost daughter. Thank you on behalf of everyone with Albinism. Good Karma is waiting for you ahead".

Florence Mithika



Dear Dr. Prabha Choksey

"I would like to thank you for playing a very important role in my life and enabling me to come this far.

My journey as a lady living positively with Albinism has not been easy but thanks to the love and support from my family and special people like you. I have now grown to be a confident person living with Albinism.

May God bless you abundantly".

Grace Nzomo



Dear Dr. Prabha Choksey

A selfless tender mother you are

For you took me in loved and cared for me despite for who I was

You are Mother to me and to us all

Partial patient and just you are

For you took me in never judged me

Yet still protected me and defended me from all criticism and harm

Mother a defender of mine and to us all

A mentor and supporter you are

For you took me, educated me

And shaded light on all my endeavors despite for who I was

Mother a role model of mine and to us all

Grateful thankful and blessed we are

For the remarkable work you are doing for us

Let us also go out to the world to reflect your teachings

And let the world know we are Dr. Choksey's children

and are **HELPED EVER AND HURT NEVER!**

Asante Mama!

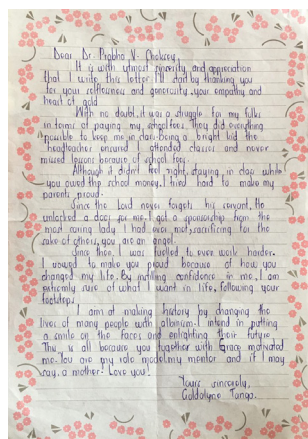
By Allan Herbert



Dear Dr. Prabha Choksey

Mum I do not know where to start with you. Your support did not come once, not twice either, you did not stop at 3 ways you could help. I have personally lost count. I will forever be indebted to your kindness in heart, spirit and material.

Jairus Ongetta





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