

Albinism & I

INFORM | CONNECT | EMPOWER

JUNE 2020 ISSUE

MADE TO SHINE

Uganda's PWA Degree Holder

The Little CHINESE BOY

Are you sure this baby is not Chinese?

PE-Kenya
@10

AMANI FOR ALBINISM

DISCOVER

NODUMO NCOMANZI

MHM Initiative
From Tears to Cheers

Be Inspired by the **Climb for Albinism** exhibit

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One foot in front of the other, I will keep Climbing



Mariam Staford - Tanzania
The climb to conquer stigma and discrimination

Editorial

Since 2010 when Positive Exposure-Kenya was born to address the plight of persons with albinism in Kenya and beyond a community of high alert, we have put many efforts in changing the narratives that surround albinism and resources like the ALBINISM & I magazine will be a breakthrough in doing exactly that and ensuring that persons with albinism continue owning their stories and narratives. Highlighting & Understanding albinism to demystify the myths and misconceptions that surround the condition remain our priority.

The articles in this first edition in times of a global crises COVID -19 have been submitted by persons with albinism , their relations and key actors in the work.

They represent the situation of persons with albinism across different walks of life. We hope they inspire you our readers as we continue to shine the albinism awareness light in this MADE TO SHINE inaugural edition!

Enjoy the read!
PE-Kenya
Advocacy & Communication Desk.

For feedback & Submissions for our next edition, please email:
contact@positiveexposure-kenya.org

Message by **Peter Muchiri** Chairperson Board of directors **NCPWD**

This is the fifth International albinism awareness day celebrations being observed in Kenya. In 2014, the United Nations proclaimed 13th June of every year as the international albinism awareness Day, the date of June 13th was chosen because on that day in 2013 the United Nations adopted its first resolution on albinism. This year, the Council planned to mark this Day in Mombasa but with the adverse effects of COVID-19 we resulted to celebrating this day virtually across the country.

During International Albinism Awareness Day, we focus on raising public awareness on albinism and preventing attacks and discrimination against persons with albinism. National Council is proud to be associated with this Day. Marking the Day is of great significance in celebrating the achievements of persons with albinism and also creating awareness on albinism. It offers an opportunity for all of us to reflect on the challenges faced by persons with albinism and to educate the public on issues affecting persons with albinism with a view to eliminating discrimination, stigmatization and violence against persons with Albinism around the world. We also consider this day as a time to



honour all those who steadfastly continued to fight for the rights of persons with disabilities.

As a council for persons with disabilities, we are cognizance of the fact that despite the many laws and policies that protect the rights of persons with albinism and those with disabilities at large the level of awareness on issues of albinism is still low. The National Council for Persons with Disabilities support person with Albinism through procurement and distribution of sunscreen lotions, Sun protective gears such as reading glasses, wide brimmed hats, long sleeves T-shirt, general awareness campaigns and skin cancer awareness and treatment.

In this financial year National Council supported about 1,000 Persons with Albinism with cancer screening and out of this number more than 20 cases were identified with advanced conditions and the Council supported them for treatment in both local and national Hospitals. reducing stigma and recognizing the achievements made by persons with Albinism.

INTERNATIONAL ALBINISM AWARENESS DAY 2020

The Government also conducts countrywide awareness creation aimed at demystifying and reducing stigma and recognizing the achievements made by persons with Albinism.

As we mark the International Albinism Awareness Day 2020 especially with the advance effects of COVID-19, it is my humble request that all of us will step up the fight against exclusion of persons with albinism in sharing information. We all have a duty to ensure that no one is discriminated against in any sphere of development. Particularly, I wish to urge families that have children with albinism to appreciate them and provide for them like the rest of their children. Give them opportunities to compete with the rest openly.

I also wish to call upon employers to employ persons with albinism. Many persons with albinism are highly qualified and skilled but are unable to secure employment due to discrimination by potential employers. As a country, we cannot achieve the Vision 2030 when a section of the population is experiencing marginalization because of their disability.

Marking the Day is not an end in itself. There is need for renewed vigor in fighting for the rights of persons with albinism and especially the fight against persistent murder of persons with albinism for ritual purposes. Let us all join hands in the fight against all forms of discrimination of persons with albinism. We also wish to urge all persons with albinism to make use of the various services offered by the National Council for persons with Disabilities, which will go a long way in improving their wellbeing and more importantly in empowering them so that they too can contribute to development of our nation. Our services are offered in all the 47 counties countrywide.

Lastly, on behalf of the National Council for Persons with disabilities, I wish you all an enjoyable celebration during the 6th International Albinism Awareness Day stay safe.

About a year ago I graduated from Middlebury College, a small liberal arts institution in Vermont, USA. About 24 years ago I was born in Shashemene, Ethiopia and at that time no one could have foreseen that one day I would be graduating from such an elite university. Several doctors and relatives warned my family that my life would not have been a regular one and that my condition as a person with albinism would have thwarted my success. There is no doubt that albinism has imposed on me a variety of bar-

riers but it has also made me a resourceful and resilient individual that loves turning challenges into opportunities.

One of the proudest means in which I have turned my condition into a positive tool to serve others is through the establishment of an organization called Amani for Al-

Amani for Albinism which seeks to promote the social and economic well-being of Africans with albinism

binism which seeks to promote the social and economic well-being of Africans with albinism through personal and professional development workshops. In the summer of 2018, in collaboration with a few other organizations, Amani for Albinism hosted an inaugural Youth Summit in Meru, Kenya.

At this occasion around 30 young Kenyans with albinism gathered to discuss personal challenges as PWA and to gain or improve a few leadership, entrepreneurial and personal growth skills.



MERON

An important component of this event were the guest speakers which included a variety of professionals, leaders, and entrepreneurs with albinism who shared their stories and their paths and encouraged the participants to fight for their dreams and desired life goals defying any obstacles others might impose on them. Such speakers included Positive Exposure - Kenya's ED, Jane Waithera, Meru County Director of Special Programs Kimathi Ngari, Human Resources professional Grace Nzomo and banker Lenonidah Anyoso.

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Amani for Albinism is an initiative that was inspired by a variety of personal and professional development programs I was able to take part in while in high school and university. Such experiences have shaped me and have encouraged me to seize any opportunity available to me by maximizing the resources I have and by turning obstacles into a chance to grow.

These same values of optimism and resourcefulness is what Amani for Albinism wishes to inspire in people with albinism (and their families) across the african continent and the globe. We might have been born without melanin in our skin and/or eyes, but beyond that, we are not different from others and it is up to us to show society that we are all "Made to Shine."

BRAVE HEART

I was born to win. Everyone in this world is unique. Even identical twins. Though they may look alike, they still have aspects of their lives that are different and that's how we are able to tell one from the other. We have different likes and dislikes, different talents and abilities. I believe that's what makes this world a beautiful place.

Hallo! I am Cynthia and I'm nine years old. Even at my age, I know I am an important part of God's creation with something unique to offer this beautiful world. I still haven't figured out exactly what that is so all I'm doing is giving my best in all that I do. I work hard in school and also take time to do other activities that interest me such as Music and Art.

I believe I was born to win and I am grateful for supportive parents. Their encouragement and my focus in learning has seen me excel in class as well as nurture my talents. More often than not, I lead in my class.



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I'm not much of an outdoor activities kind of girl. This is not because I don't like it but because of a skin condition. Oh Yes! I was born with albinism. To many, this might seem like something dark, limiting or pitiable but to me, it is all part of my uniqueness. It cannot in any way stand in the way of me getting what I want in life not unless I let it. I can confidently say this especially when I think of someone like Helen Keller. She was blind, deaf and mute, but this did not stop her from becoming an inspiration to many people all over the world. She achieved more than what many able bodied people with all their senses intact ever achieved. Therefore, nobody can convince me that I am not a winner.

At this point in my life, I know it is important that I remain focused on my education, and school activities that help me nurture my talents. I will keep the right attitude in all that I do and remain optimistic that my future is loaded with greatness. In my mind, even with all the challenges that we face every day, the world is still full of unlimited possibilities.

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FROM TEARS TO CHEERS

Albinism to me was not quite a surprise or a far away thought idea when I was born. I was born in a family which had a kid with albinism already. My brother. Welcome to my world of albinism and how we are made to shine contrary to the expectation and or perception of many.

I am Evelyn Wambui born and brought up in the ridges of the Mt Kenya where albinism awareness was not really at its best.

Growing up and learning not once nor twice would you find a group of children or even adults staring at us or shushing each other as we passed by, not mentioning the name calling such as "mzungu" My

parents having understood and being aware of albinism ensured that we got the best quality education, skin, and health care. They were always willing to go an extra mile to ensure that we would shine in whatever we were doing.

However, not each individual will be happy when they see your star shine and thus will strive to dim it so that it is not recognized. But do you let them do so? No. Today I am going to give my Shining star story that will inspire other persons with Albinism to never live in their past and desperate situations but always to look forward and be the illuminating star that will always shine for others to learn from

Four years in high school and in a mainstream school, I was pulling all my strings together to beat the odds in performing and beating the other girls in my class and school respectively. All these dreams felt shattered one evening during supper after breaking for august holidays. "Your house was razed down to ashes and nothing was salvaged." This threw me into a turmoil of thoughts bearing in mind what had informed the burning of the house, which coincided with the day, we had just returned from the midterm holidays.

To add to it, I still had a pending fee balance and I could feel as if I was now at the verge of losing everything despite having worked tirelessly to make a change in my four-year course. I would sit down and just find myself crying

trying to figure out why people had become so inhuman and indifferent to the point of wishing to wipe us out because of albinism.

Luckily with the psycho-social support of Positive Exposure-Kenya and my family I was able to overcome the grieve and pain I was going through and made a firm resolve that nothing nor anyone was going to deter me from achieving that which I had envisioned.

After the holidays, we went back to school and here I worked hard to achieve my dream and also to make proud all those who had supported me and my family throughout that period since many always felt that the incidence was going to affect my performance. I knew I had a huge task ahead of me and just did my part hoping that God would help me in the rest.



Joseph Kanyi | NATION
Mahiga Girls High School's Eveline Wambui Mwangi in jubilation at Thunguri village in Nyeri after she scored a B+. She was among candidates with special needs who performed well in the exams.

FROM TEARS TO CHEERS

Sure enough, God did hear and see my pleas as my tears and our tears were transformed to cheers. I could not believe my ears as the education cabinet secretary was releasing the results and heard my name being read amongst the top ten students with special needs who had performed exemplary well country-wide. What even made it more profound was that I was enrolled in a mainstream school and not a special school as was the case with others.

The homestead that had become dejected from the fire incidence now became a buzz with activities with ululations renting the air, media personnel streaming the compound to cover the story first and unending calls of congratulations message coming through. God had finally done it; our tears had been changed to cheers.

I could only but thank God when I kept seeing my pictures flashing on screens as well as appearing on newspaper including the national dailies. This has made me make a resolve that I am going to use that opportunity to create more awareness about albinism however little, so that people may change their perception about albinism for WE ARE MADE TO SHINE.

Currently I have been called for a Degree Programme in one of the best Private University In Kenya. Mt Kenya University to pursue a Bachelor in Economics and Statistics I believe it is also an opportunity for me to prove to the world that I WAS MADE TO SHINE.



Nodumo Ncomanzi - Zimbabwe

We can only be true to what we climbed to stand for social justice



Lady Maah Keita - Senegal

When our confidence grows, we can reach our goals and that is boundless

Greatness comes from small beginnings



It all began quite innocently enough on the remote rural island of Janjanbureh in The Gambia. It was a year with plenty of rain and all the women of the community filled their 'buntungos' with rice as the harvest was bumper. Mum however, missed this because daddy had instructed her not to farm the fields that year as the new coloured baby required great care and cannot withstand the heat of the sun in the fields. This was revealed to me by my grandma some twenty years later during our casual conversations around the fire that was often lit at the center of the compound to warm us from the freezing tropical monsoon cold.

Mum also later revealed how I would usually cry my small eyes out during my late evening warm water bath and during the day wrapped in multiple blankets to shelter me from the ultra violet rays. Often, my grandma jokes about how Dad, riding grandpa's 'iron horse' on that fateful evening broke the news of my birth to the women of our compound who were gathered under the neem tree situated at the corner of his big brother's house. The women of the compound often sit under this tree after the completion of their domestic chores to drink 'attaya' and chat away whilst simultaneously preparing for the next day's work routine.



I however do not have many recollections of my early village life; apart from family photos and funny recollections from grandma of our summer holiday troubles. I left the care of my mum at the age of two. My uncle, who was at the time a teacher in a far-away region, heard of me and when he came down during one of the school holidays. He convinced Dad that I should travel with him to the city so I can be close to facilities and health care if the need arises. There I would also have the opportunity to attend school under less harsh conditions. Dad was content and I traveled with Uncle to the city. 'T Town' became my new abode since then and the rest they say is history.

My journey as a child with Albinism has not been all that rosy. From Kinteyh Kunda Jannehya Primary School to Nusrat Senior Secondary School and later to University of The Gambia I went on to become a Chevening Scholar recipient. I have along the way struggled with myths and misconceptions about my condition. I vividly remember being bullied by my peers to the point where I will avoid participating in the moon light children's hid and seek game, skipping school and sometimes isolating myself to cry and wonder why I was receiving all this discrimination and exclusion. Around town I am called 'Pouneh Nawet' (a term I still don't know the meaning). Some move away as I sit close to them and others spit on the ground for fear that they too will have a child with Albinism.

I went through the rigor of schooling copying notes from colleagues as low vision prevented me from reading clearly from the blackboard, no magnifier to support my reading of textbooks and school computers had no zoom software. Sunscreens, shades and UV protection clothing were hard to come by as poverty takes a toll on my family.





With perseverance, dedication, commitment and hard work, I weathered the storm, stayed focus on the price. Despite so many trials and tribulations, I am still standing strong, shining my light, as I know I am made to shine.

About the Author

Gibairu Janneh is a 2015/16 Chevening Scholar, an International Development and Communication Specialist. He has several years' experience in Strategic Communication, Journalism, Project Management and Media Advocacy.

He is currently the Director of Communications at the Parliament of The Gambia, a blogger and youth activist. He is also the founder of the Association of Gambian Albinos (AGA), an advocacy based youth organization engendered to campaign for and support persons with albinism in The Gambia.

His research interests include Governance, Poverty Alleviation, Gender, Community Development, Sustainable Development, Informal Rural Economies and Sustainable Livelihoods.



PWA and Career



While growing up, people with albinism are often told that we can only pursue a few career opportunities. This section on the Albinism and I magazine will be dedicated to debunking this myth by sharing that PWA can (and have) pursued a wide range of careers. In Kenya, many PWA are made to believe that becoming a teacher is one of the only career opportunities that will be a viable and respectable path. However, this is actually not the case. Although, if one is really passionate about education and about teaching the next generation, becoming a teacher or a special education teacher can be an ideal path, for all those that have other dreams this rubric will introduce you to some exciting and unique paths that you might not have considered and will offer career tips.

Did you know PWA are lawyers, doctors, scientists, writers, models, tech professionals, make up artists, human resources officers, bankers, business owners and even ambassadors?! These are just some of the few paths that, through hard work and dedication, any PWA can aim for. Although there will be a handful of jobs we might not be able to fully accomplish because of our eyesight, many other roles can be filled if the appropriate accommodations are offered. In any job you should feel empowered to ask your employer to provide any type of measures that will make your day-to-day work more feasible. Such measures can include working in an area that is more covered from sunlight, using a magnifier to read fine text on

printed documents, or a bigger monitor. In the coming issues of this magazine we will share with you more in detail the path of some of the careers we have mentioned above to further highlight the resilience and strength all PWA share.

Written by MeronBenti, Founder and CEO of Amani for Albinism and recent university graduate from Middlebury College, USA

POSITIVE EXPOSURE-KENYA @ TEN YEARS OF IMPACT

Organization Background

Positive Exposure-Kenya (PE-KENYA) is non-profit organization that deals with the well-being of the albinism community by challenging the stigma, fear and discrimination in relation to albinism and supporting positive social change in Kenya and across other African countries. PE-Kenya was founded by Jane Waithera (Executive Director) in 2010 and was officially registered under the NGO'S coordination Board in 2011.

VISION

- To see a more compassionate world where difference is humanized, embraced and celebrated.

MISSION

- Promoting human dignity, respect & acceptance for Persons with Albinism (PWA) and their relations by improving their lives and changing public perceptions on albinism.

OUR CORE VALUES:

- Human Dignity & respect
- Equality & Non Discrimination
- Innovation &creativity
- Team Work & Partnerships
- Integrity &Transparency

OUR PROGRAMS/ PILLARS

- ALBINISM AWARENESS & ADVOCACY (AAA)
- SOCIAL PROTECTION (SP)
- SOCIO ECONOMIC EMPOWERMENT (SEE)

PE-KENYA MILESTONES:

- **2010:** Inception, the organization positive Exposure-Kenya founded
- **2011:** PE-Kenya officially registered under the NGO'S Act
- **2012:** Understanding Albinism forums launched. The forums are aimed at changing the public perceptions on albinism by sharing the facts on albinism with the public
- **2013:** Commencement of social economic empowerment & development initiatives (SEED). This is the SEE arm that promotes skills and business support to the beneficiaries
- **2014:** On Beauty documentary
Launch of PE- mentorship program
- **2015:** KANTHARI documentary, Change from Within
- **2016:** Art for albinism
- **2017:** CASA (Community Awareness sessions on Albinism),

CLIMB INCEPTION

- **2018:** CLIMB FOR ALBINISM
- **2019:** ALBINISM & I APP
- **2020:** Digital Campaign on albinism - (E-Magazine, digital exhibition on art for albinism)





Climb for Albinism Kilimanjaro : 5,895m, October 2018. JW

Steve Lipp
© 2018

Sassy, Humorous, Intelligent, Nerdy, Exquisite.



My earliest childhood memories include a learning how to wear sunscreen from loving parents, playing with scorpions on the porch of our small blue house, and being constantly, aggressively reminded by strangers of all ages that I was different. I remember looking at my family then back at myself, and wondering why. For a long time as a child, I felt like I was probably the only person who looked like me.

The internal isolation of my early years is something I can't quite explain. It would really hit me when other children bullied me. "The thing" was how the mean little ones in my small town referred to me. I carried that trauma on my own. We didn't really talk about my albinism at home.

But a music video unexpectedly changed my life on a random evening. Six year old me was watching a show called Afrobeat, when Salif Keita came on singing Nou Pas Boujer.

As an adult, I have once revisited this moment with my parents. According to them, I went very still, and wouldn't stop staring at the TV. "Hypnotized" is the word my father used.

You have to understand that until Salif Keita coincidentally sang and danced into my life through the TV, I had never seen anyone like me. I did not know there was anyone else like me. My memory recalls a feeling of being frozen in time as I discovered I actually wasn't the only one. The shock has stayed with me. It remains one of the most uplifting emotions of my life.



If you don't know Nou Pas Boujer, it is like a beautiful, spirited, loud fighting anthem. Salif sings and dances on screen, and in some scenes he leads a troop of vibrant masked dancers. He looks powerful. And even with skin like mine, he looks like he belongs.

I cry a little when I think about the moment that made albinism a condition "we" have, and not just me. The kind of validation I received could not be replicated. Validation that only comes from knowing you are not in a bubble. Validation that only emerges from being exposed to positive depictions of people who share unique parts of your lived experience.

My parents say that after the the song finished, I desperately wanted to know how someone who looks like me could possibly be on TV, in the homes of many. I was amazed to learn of Salif fame as a musician.

Until he was broadcasted into my life, I just assumed that there were certain things I would never be allowed do because of my difference. Like singing and dancing on TV.

Seeing Salif on primetime, and watching him be the artist he is helped me realize that perhaps I could be more to the world than just othered.

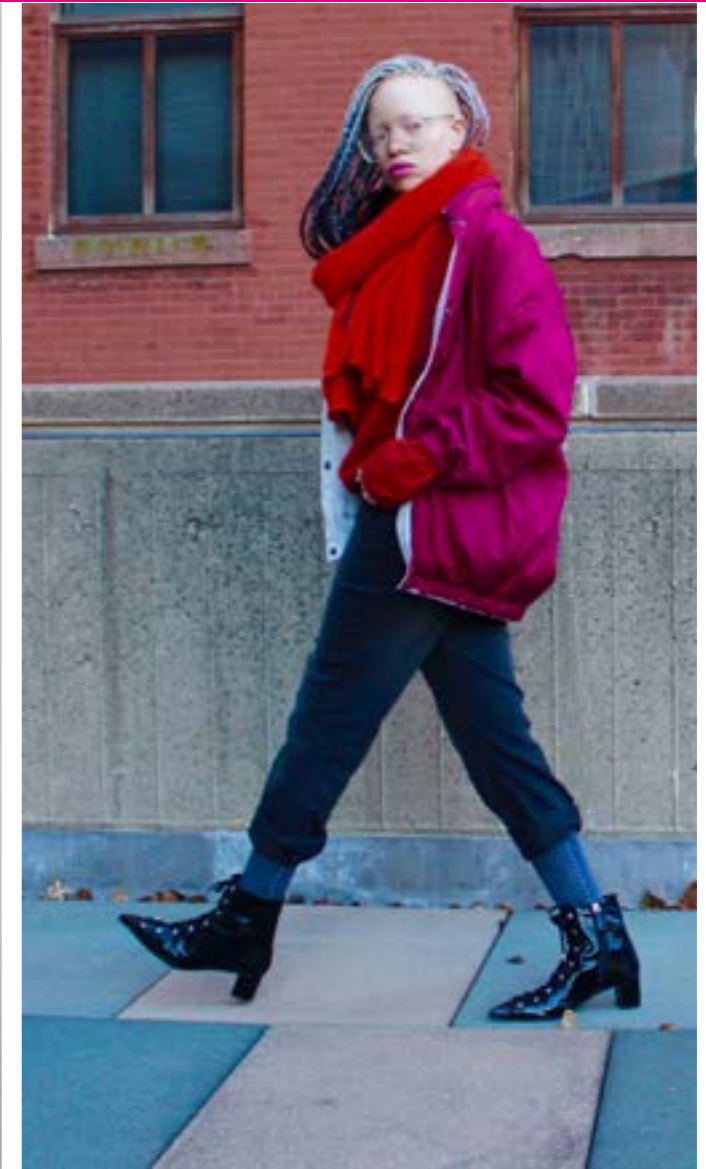
The only public opinions I knew about albinism then were negative opinions. Cruel opinions. Especially from adults. Passing strangers were never afraid to express how a little albinic girl made them feel uncomfortable, or even offended them. Obviously, I'm articulating my childhood thought process in my adult state. But each time someone would stare at me, point at me, laugh at me, insult me or try to touch me, I had no mental reminder that I was whole and valid outside of their responses to my appearance. Until I saw Salif Keita on TV, and saved that memory forever.

Representing ourselves and seeing other like us in the same spaces where the rest of humanity operates, is a basic human right for all people with albinism. Being allowed to live, work and create however, and wherever we want to is a step in countering the constant negativity that we often have to endure.

The affirmation I received that night had carried me my whole life. And children with albinism, people with albinism deserve continuous streams of it. Representation matters.

SHINE

Sassy
 Humorous
 Intelligent
 Nervy
 Exquisite





Regina Mary Ndlovu Kabosha - South Africa

Voice Albinism The New Era



Jane Waithera - Kenya

Our Footsteps in the mountain towards a just society are uncountable and in erasable!

Inspire: Engage: Transfrom

The little 'Chinese' Boy



"Are you sure this baby is not Chinese?" asked my OB/GYN as I lay on the table in the cold operating room as he held my precious little boy upside down and spanked his bum to get him to 'open his lungs' as the medical fraternity is fond of telling new moms.

"Let me call the other nurses to see this!" quipped one nurse in the room as the rest of the team giggled and laughed and made fun of the situation.

"Can't you people tell he has albinism" I retorted groggily. I was at the time heavily sedated and my head felt very light. If my physical condition would have allowed it, I would have probably smacked the daylights out of them as I rolled my eyes.

This was the world my little ball of sunshine was coming into- a world of ignorance, arrogance, misinformation, folklore, archaic cultural practices and just sheer inhumane treatment. I could already feel my heart sink imagining the battles we would have to fight with my little angel, but I was armed.

Dear reader, you would be forgiven to imagine these events happened in some ill-equipped hospital deep in a shady valley in the country-side without trained medical personnel but alas! It happened right here in Nairobi, in a well-known reputable hospital. But as mama said, she was armed.

Fast forward to our first few weeks home and the usual questions from friends and family that I had by now learnt to ignore or educate based on your tone of voice. "why is your son so light?", "why doesn't he seem to be catching up on his visual milestones?", does anyone in your family have 'this condition'?", "has you husband accepted the baby?"

It was even worse when he learnt to walk and we started going out with him like any other family. The stares in the mall, church and any social place were a tad too much, but baby and mommy are made of steel- we walked with our chins up high and gave you 'the look' if you stared and pointed. With time, our little community had adjusted to having us around and had hopefully learnt a thing or two about albinism.

I love to read and generally would research on how to make the surroundings conducive for our little guy- adjusting the lighting to suit his eyes, wearing a wide-brimmed hat when going out, applying sunscreen religiously (while avoiding the eyes), wearing long-sleeved items of clothing which had the ability to reflect the sun's rays and so on and so forth. Unfortunately, mama didn't quite complete her research with vision and therefore enrolled the young man into the playgroup without having his visual acuity checked!

Everything at school seemed to be going great- the young lad had learnt a number of rhymes, could count, recite the alphabet and even enjoyed music class. Mama finally felt at ease, the future was bright for her young man. You can then imagine my disbelief when the school invited us for a parents' meeting and our young man couldn't identify any of the numbers or letters he had been comfortably reciting and to make matters worse, he was sitting at the very back of the class because his teacher didn't want to handle a child who 'couldn't see' and she was afraid of raising the issue with his parents. (This cost us a whole year of schooling by the way but story for another day.) She even suggested that he would do well at

Thika School for the Blind and because he was young, he would adjust pretty fast and we therefore shouldn't waste time enrolling him there.

I was on the hunt again this time for a good ophthalmologist and since I had already made a few friends who were persons with albinism, I landed on a doctor almost immediately. I poured out my heart to her and she in turn held my hand and that of my little boy on this great journey we've been on. She did confirm that the young man wasn't blind but obviously had a few challenges with his eyesight though nothing that couldn't be worked around. We had our very first pair of spectacles at three and our world changed dramatically as well as positively

For starters, the young man loves his musical instruments and he also loves athletics! Can you imagine? For a child whose first teacher dismissed him as blind! Anyway, it has currently been six years of schooling and trying out his hand at music and athletics and I can see we're heading somewhere. I mean, this young man actually competed in athletics and was among the top three fastest runners in his category. To add onto this, he has become so good at music that he plays the xylophone during school events! These may look like small wins for us but for a child who was once labelled 'blind', we don't take it lightly and we thank God for his grace upon his life as well as an excellent support system and teachers that understand and nurture him.

The 'young man' mentioned here is called Ivan, son of Victoria and Gilbert Robi who lives in Nairobi, Kenya. Ivan is eight years old and is in grade two at an integrated school.



THE FACE OF CHANGE

My experiences with discrimination are less severe than the experiences most people with albinism have had. The circumstances I grew up in, the schools I went to and my professional training all helped make my life and experiences less difficult than they would otherwise have been.

However, my life has not been smooth sailing. It has never been easy especially when a large proportion of society is avoiding you. When I was growing up, I was always the centre of attention in every crowd I was brave enough to appear in. As a child I would pass through a crowd of kids and I would have around 20 or more kids following me chanting 'Mzungu'. In other crowds when I walked by, some voices were loud while others whispered. Nevertheless, they all analysed me, mostly in disparaging terms. I soon developed a defense mechanism which was to be friendly and welcoming and with time, I was the most loved in the village.



“ As a child I would pass through a crowd of kids and I would have around 20 or more kids following me chanting 'Mzungu'.



Growing up, there was always little information around me about albinism, so I scoured every little bit of information from reading books and magazines. I knew I was to avoid the sun at all times to prevent sunburns. I didn't see or use sunscreen until I was about 15 years of age when my sister brought to me a tube she was given as a gift by a white man "muzungu" in the hotel she was working at in Diani.

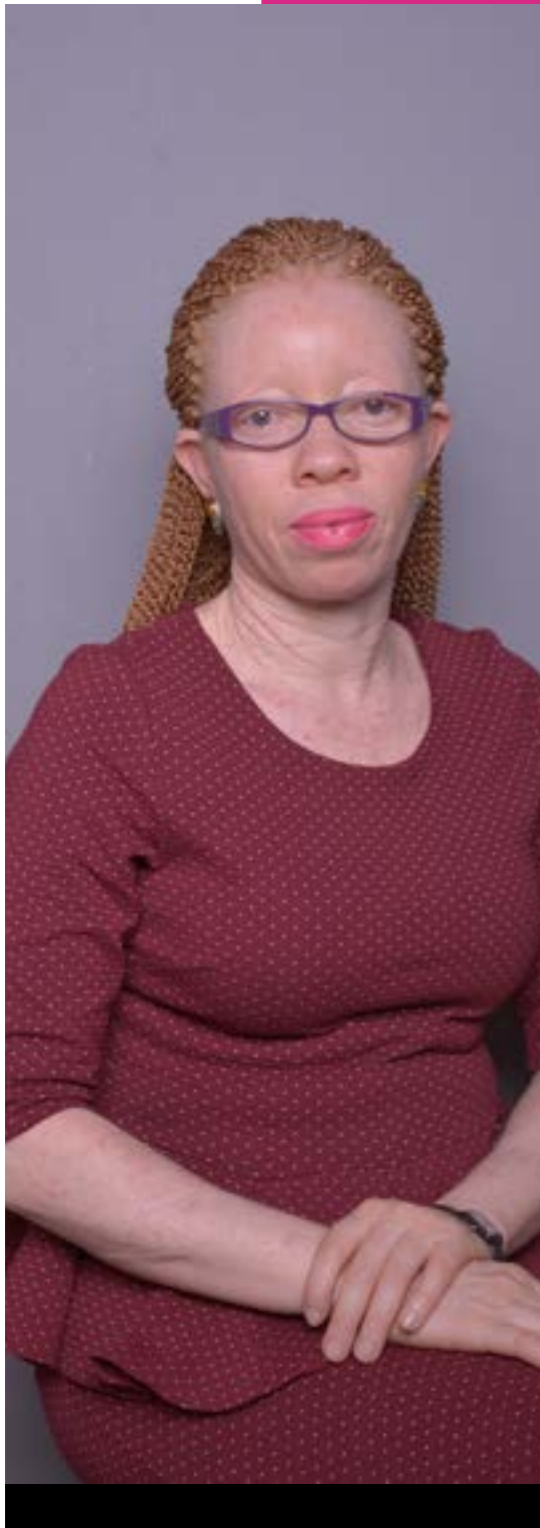
I excelled through school and graduated from Jomo Kenyatta University of Agriculture and Technology with honors in BCOM-Finance in June 2014. For six months I was tarmacking for a job. An opportunity presented itself in December of the same year for an interview with Barclays Bank Kenya (now Absa Bank Kenya). Because I understood and accepted my condition, I had no problem explaining the condition of my eyesight and the kind of assistive devices I need to make my life easier during the interview and later at work if I was to be successful. Gladly I did well in the interview and was posted to one of the biggest and most busy branches.

Working at the bank in the Branch Network has been the most exciting experience of my life. It has not only taught me on how to deal with different personalities but has also given me vast experience in customer service skills and digitization among other skills. The challenging work environment with difficult customers, deliverables and meeting deadlines has also taught me to exercise patience in all that I do for the best performance. With my gained expertise at work I was recently accorded with the position of being the Face of Change when the bank transitioned from Barclays to Absa bank Kenya

I have been an inspiration to both people with albinism and those without. It's always so fulfilling when I receive compliments from colleagues, customers, peers and family on excellence at work and my confidence.

I have a great personality, friendly and my all-time MOTTO is kindness. Albinism has taught me that people will treat you in the manner that you treat yourself. Therefore I love my self and have high self-esteem and believe that I AM MADE TO SHINE.

MADE TO SHINE



Olive is the Executive Director at Albinism Umbrella, a nationally registered NGO in Uganda. She is among the very few PWA who hold a Bachelor's degree in Uganda, The Bachelor of Commerce graduate from Makerere University could not settle until she obtained professional certification of ACCA. (Association of Chartered Certified Accountant). Being a professional accountant, the sky was no that limit to the opportunities of this determined Ugandan.

Olive has been privileged to work in different organizations like the energy sector at Chevron Uganda, the microfinance industry at Vision Fund an affiliate of World Vision and the banking sector while at Postbank Uganda. She also served in a disability child organization (Uganda Society for Disabled Children) whose seed later blossomed into the establishment of Albinism Umbrella.

Olive has advocated for PWA in Uganda at different fora including the Parliament of Uganda, diaspora at the 7th Uganda UK convention in London and supported many locally. She is the brain behind the annual Parliamentary fundraising walk spearheaded by the Right Honorable Speaker to raise funds raised for the construction of a rehabilitation and skilling center for PWA.

All the above was made possible from her loving family and the acceptance she received from her mother who dared to believe that she can indeed shine. Her mother's continued support and encouragement were strong foundational stones to enable her achieve this and more which is yet to come.

You too can provide a conducive environment for PWA to achieve their full potential- Made to shine!!!



My Golden Baby

The only time a baby's cry is music to those around is when the baby is born. The outburst brings tears to everyone's eyes because it is an indisputable indicator of life; of hope. The then exhausted mother holds her baby in her arms, tired yet strengthened by the wholesomeness of life the baby brings. Cynthia's birth was not different at all. Holding her in my arms, a fragile little being that she was, so many thoughts came to my mind. I was overwhelmed with fear when I thought of what the world might do to her, but something changed when she opened her eyes and looked into mine. Enormous courage shone right through them and her smile made my heart leap with joy. "This is it," I thought to myself, 'the moment I have been eagerly waiting for!' She quietly spoke of uncontainable strength and from then, I knew I had to join her. I had to be brave for her, stand up for her and be her voice until she could finally with her own words and actions, do this for herself.



Nine years later and I've never been so honored and proud of who my little girl has turned out to be. Cynthia is not just the kindest person I have ever met, she has the ability to create an aura of joy everywhere she goes. Her mastery of the piano is quite extraordinary and I have never heard anyone play the glissando so perfectly at such an age. She has aptly nurtured the skill of being heard without having to necessarily utter a single word. I take great pleasure as a parent in knowing that she has carefully learned to speak her mind and express her voice in a way that is so unmatched. Her capacity to remain calm in the largest of crowds and congregation still dazzles many. I would never have thought that at her age, she would be so bold musically speaking and to a congregation of believers or even a larger multitude at school functions.

Besides being well skilled in playing the piano, Cynthia has also worked to ensure that no one else ever beats her in class. Her untainted academic record since she became of school going age leaves me speechless all the time. I have had to work so hard to keep up with the energy she brings with her in everything she endeavors to do. There are those times that I am afraid I will drag her behind, but her desire to keep on being the best reminds me that she indeed deserves to be nothing but just that.

I have never quite understood how at her age, she can do so much, and with so much ease. Her love for art is inexplicable and she is currently working on a collection that details the Covid-19 experience. I would never be able to totally describe what her presence in my life entirely means, because words would never be enough.



Meet 12 year Old Aga.



When he was younger, I would point out, "Oh he has Albinism!" Well, not anymore nor does anyone around him for that matter! Aga is a wonderful 12-year-old boy who has defeated all odds. When he is not playing video games on his laptop, making music or riding his bicycle, he is opening a Nerf gun to change its settings so that it can shoot several more times. Yes, despite his impaired vision he can screw and unscrew screws that are a few millimeters!

Aga has Albinism and up until a few years ago, that defined him. He is now a confident boy who found his voice and the love for sport in Kenya in 2016. He constantly reminded people that his vision may not be 20/20 but he still saw reasonably well and should never be left out. He has proven to be quite a sports man. He is very articulate, can explain what he can, and cannot do, pertaining to his condition. Aga was able to get the ball in his hockey games changed for him. Just because he could not see the white ball it did not mean he could not see the yellow ball. Within a few terms, Aga has moved from Group D hockey to a much-coveted position in Group B!

We had anticipated that swimming would be a challenge because the swimming goggles would hinder his vision. However, he soon learnt how to navigate the waters and swim in a straight line without relying on seeing what was ahead in his lane. Nevertheless, this does not stop him from having fun splashing in the water.



We all thought he could not ski and would say, "Let him just join in the fun." He however proved to be a natural skier! Just after a few sessions he was able to go down the Swiss slopes without any support. It is a pity that because of Covid-19, he was unable to earn his last badge and move to 'advanced skier'.

Again, we never wanted Aga to try the 21km bicycle challenge. Why? It would get too hot and he would burn. He soon came up with his own gear consisting of a balaclava, mommy's stocking and a large brimmed hat. He was not the first to finish the 21 km obstacle challenge, but he was the captain of his team and helped navigate the route.



Aga has always loved to run, but we had never thought of it as more than just a hobby. However, he has soon become the star of short distance running.

Aga loves music and is never shy to try a new instrument. He has struggled with learning to read music and play the piano, but he has kept at it. Now, he can confidently play in a concert. He is also able to create his own music using musical computer applications

Indeed Albinism does not define Aga. Aga is a 12 year old who is looking to become a teenager and move on to Secondary school.





ALBINISM ACTIVITIES IN RURAL KENYA

JUNE 2019 – to date

Addressing rare conditions and actively supporting marginalized communities has always been important to Boehringer Ingelheim. Since 2004, Boehringer Ingelheim has participated in the EURORDIS Round Table of Companies to raise awareness of rare conditions such as Cerebral palsy, Scleroderma, Albinism, and others and the impact they have on affected persons. Under the umbrella of the Making More Health initiative, Boehringer Ingelheim since July 2019 started to engage in Kenya directly “on the ground” and to empower people with albinism in many ways and in close collaboration with local NGOs, social entrepreneurs, and albinism communities.

The stigmatization of people with albinism is very high in African societies due to visual disability associated with the condition and pale color that makes people with albinism stand out. The marginalization for people with albinism is obvious and being a person with albinism means often to become a victim of superstition, discrimination, and violence. Often, people with this condition and their families, live close to the poverty line. They have few or no treatments available; they are unable to get jobs and not well integrated in schools and in public. There is a lack of knowledge and awareness about the albinism condition in society.

Making More Health (MMH) is an initiative by Boehringer Ingelheim and Ashoka to create healthier communities and sustainable ecosystems of change through social innovation.

MMH has committed resources in rural Kenya to create a fully inclusive society that supports the wellbeing of people with albinism. Our goal is to create an inclusive society that integrates and supports people with albinism by demystifying myths about the condition through leveraging education and raising public awareness. Together with our local partner NGOs Positive Exposure- Kenya, located in Nairobi and Golden Age Albinos Support Program (GAASP), located in Webuye we are committed to making a real change for better happen.

Using a similar social support model as PE-Kenya, together with our partner GAASP we have created five albinism social support groups that currently have 85 members comprising men, women, and children. Members meet monthly to offer mental support, share knowledge on health-related topics as well as engage in economic self-development activities e.g. liquid soap production, poultry farming, animal husbandry, artwork, and bead making. MMH also supports the ‘Supporting Entrepreneurship and Economic Development’ (SEED) project that targets households impacted by albinism to equip them with skills and to become economically self-reliant. We work together with our communities on solutions to meet their albinism specific needs like eye care and skin care. MMH employees engage in training our communities on the ground, co-create, and develop materials that are shared then within the network of partners.

In collaboration with our partners, we have implemented initiatives to create a conducive learning environment for students with albinism by educating school administration, teachers, and students on the condition. Together with Positive Exposure, we ensured 30 students with albinism who previously enrolled in special schools attend regular schools and provided with reasonable accommodations like prescription glasses, telescopes, and large prints. We provide mentorship to these students who eventually they compete nationally with outstanding performances.

End poverty for people with albinism in rural Kenya - SDG 1.

- We have promoted the access to basic needs mainly food, shelter by providing immediate support in the shortterm and engaging families of people with albinism in income generation activities.
- Safe shelter and clothing provided to 40 families living in abject poverty. This includes provision of a house, bedding and clothing.





COVID RESPONSE 2020

30,000 Euros donated as emergency response fund to our community in Western Kenya. During the COVID-19 lockdown, the funds were used to purchase food packages delivered to 650 families including homes of people with albinism and those of the elderly on a quarterly basis. People with albinism who were previously trained on hygiene and safety have become ambassadors of hygiene and sanitation in the community. Utilizing the knowledge from trainings, to install tippy taps, produce soap, and share learnings/awareness about the importance of hygiene. At the onset of the COVID-19 pandemic, they set up hand washing stations and distributed soap to the vulnerable members of society. Over 1000 community were supplied with soap and hand sanitizers, taught on proper handwashing, supported with face masks including the public transporters (BodaBoda drivers)

Additionally, the community prepared a freely accessible video on how to make liquid soap. The video is available on this link <https://my.makingmorehealth.org/download/how-to-make-liquid-soap/>

These achievements show that persons with albinism are made to shine when a conducive environment is provided to nurture their talents and skills. Beyond the International Albinism Awareness Day, we aim to create a sustainable platform for dissemination of information regarding the albinism condition and other health-related topics on my.makingmorehealth.org. We are proud to accomplish these milestones with the support and collaboration of our partner Positive Exposure-Kenya and call upon other corporates, individuals and interested stakeholders to collaborate with us to create a fully inclusive society that embraces diversity and inclusion of all persons.

For more information, please have a look at www.makingmorehealth.org.

Strengthen the means of implementation and revitalize the global partnership for sustainable development - SDG 17.

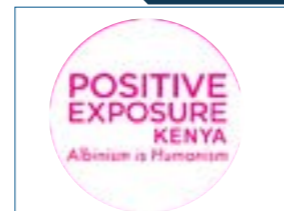


To ensure sustainable implementation of our projects we rely on support from the locals. Our main partners in this project have been:

Government of Bungoma Count

Schools

Faith based organizations



Understanding ALBINISM

What is Albinism?

is it...

- .. a disease?
- ... contagious?
- .. a curse or punishment?



or is it...

- .. a condition?
- .. non-contagious?
- .. genetically inherited?



What do you call me?



- 1 Avoid use of derogatory language eg. Zeruzeru, Albino, Mzungu, Pesa.
- 2 When dealing with any condition, it is better to use **person centered language**.
- 3 Saying person with albinism considers the person before the condition.

Albinism is Humanism

David - Canada **Mary - Puerto Rico** **Sisters - United Kingdom** **Isabella - Cameroon** **Maziah - Malaysia** **Enoke - China** **Desha - Russia**

Nyah - USA **Ayelle - Japan**

Graciela - Panama **Rose - India**

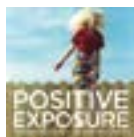
Siti - Mali **Mary - Fiji**

Amelia - Brazil **Tina - Uganda** **CP and Diptee - Kenya** **Smee - South Africa** **Tenencia** **Lauren - Australia** **Cristi - New Zealand**

POSITIVE EXPOSURE
The World of Albinism
www.positiveexposure.org

ALBINISM WORLDWIDE
WE ARE NOT ALONE

Albinism is a non-contagious genetic condition occurring in all countries of the world. BOTH the father and mother must carry the gene for it to be passed on. Albinism is a lack of pigmentation in the hair, skin and eyes, resulting in low vision as well as vulnerability to sun-exposure and bright light.



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