

“Penye nia, pana njia”

Where there is a desire there is a way

REPORT 2022

BEYOND
SUNCARE



INDEX

INDEX

2022: Five years later	5
About Beyond Suncare	9
Beyond Suncare at a glance	13
Preparation of the 1st Strategic Plan	18
We align with the SDGs	20
Our team	26
Activities carried out in 2022	28
Other outstanding actions	58
Communicate to go further	62
Clear accounts	66
Awards and honours	68
Our impact in 2022	70

“

Sometimes we feel that what we do is just a drop in the sea, but the sea would be less if it was missing a drop.

— MOTHER TERESA OF CALCUTA



“The United Nations Development Program indicators inform us that extreme poverty, malnutrition, access to drinking water and literacy rates have reached the best numbers in history. Therefore, there are reasons for hope and to continue believing in human beings.



2022: FIVE YEARS LATER

MI feel very excited and grateful to present the 2022 Report. A very special year for Beyond Suncare, since June marked five years of our journey

Five years full of challenges, learning and shared joys. Feelings that coexist with our deep concern about a war at the gates of Europe that, although many of us saw it coming, did not believe it could happen. A war that represents a geopolitical, humanitarian and economic crisis unprecedented since the Balkan conflict.

On the other side of the coin, the development indicators of the United Nations Development Program inform us that extreme poverty, malnutrition, access to clean water and literacy rates have reached the best numbers of the history. Therefore, there are reasons for hope and to continue believing in human beings.

Our indicators are also a reason to smile. The 3,653 people with albinism that we have cared for in 2022 have better dermatological health - including a decrease in precancerous lesions - and an improvement in their self-confidence. Likewise, the progress in the knowledge and skills of the local health personnel with whom we work is notable, and their enthusiasm to continue with their efforts to reach out to the most vulnerable is growing.

We have managed to reach more people in a more efficient way with a clear commitment to continue strengthening the creation of alliances and networks, mainly with institutions and civil society organizations in the Sub-Saharan African countries where we work, but also with European foundations and companies.

We continue working on the consolidation of our strategy with the presentation of the [I Strategic Plan 2023-2027](#) and we obtained our first public financing in Spain and Malawi, where our local office, in consortium with other NGOs and with the support of the delegation of the European Union in the country, has started an ambitious project that, among other actions, incorporates into our work an element that we have been dreaming of since our beginnings: addressing the mental health of the beneficiaries with whom we work, incorporating specialized psycho-social support and placing a special focus on those people who have been victims of torture, kidnappings and serious violations of their rights.

With enthusiasm and the good work of medical associations and civil society organizations, we have started projects in very forgotten communities in countries where we had no presence, such as Uganda and the Democratic Republic of the Congo.

Our work has never been easy, the challenges are numerous and Beyond is a small NGO; a drop in an ocean, but it is our drop, your drop, the drop that is changing thousands of lives and that is more than a reason to continue fighting and working for our purpose.

I am convinced that, with you by our side, we will continue to overcome the difficulties that will arise and we will be able to continue working for the health, dignity and future of people with albinism in Africa.

Thank you for helping us make it possible!



Mafalda Soto – President of Beyond Suncare

Our work has never been easy, **the challenges are numerous** and Beyond is a small NGO; a drop in an ocean, but it is our drop, your drop, the drop that is changing thousands of lives. That is more than a reason to **continue fighting and working for our purpose.**

5 years

“People with
albinism in Africa:
our reason for being.”



“We work every day to ensure that all people with albinism live a free and dignified life, protected against skin cancer and all forms of discrimination.”

2



WHO WE ARE

Beyond Suncare is a Spanish non-governmental organization that has been carrying out cooperation actions **since 2017 in terms of development in the health sector, in countries in Development paths in Africa.**

We are a non-profit, independent, apolitical and non-denominational association that is governed by Organic Law 1/2002 of March 22, on the Right of Association, and by Law 23/1998, of July 7, on International Development Cooperation, after its registration in the National Registry of NGOs in 2020.

OUR MISSION

Our challenge is to make universal access to health a reality by promoting access to health for the population with albinism in the countries of sub-Saharan Africa and the improvement of their living conditions, always seeking to contribute in the most effective and efficient way possible to the general action against poverty based on the values of:

- **Justice**, understood as the recognition and real enjoyment by all people of Human Rights, enunciated by the UN in the Universal Declaration of 1948.
- The **equality** of men and women, boys and girls.
- **Environmental sustainability.**
- **Coordination** with other public and private institutions, in order to multiply the positive effects of cooperation, assuming the commitments of **alignment, appropriation, harmonization and transparency.**

OUR VISION

To be a **reference organization** for people with albinism in situations of greater vulnerability in the countries of Sub-Saharan Africa where we carry out our work, so that they find in our organization a channel to improve their quality of life.

Our central **axis of work is health with a rights-based**, comprehensive, inclusive and quality approach; having as direct and priority beneficiary population the albino population of the African continent.

We accompany and help the most vulnerable albino people in the African countries where we work, in raising awareness and achieving their right to health.

Our work in the countries where we work is aimed at **reinforcing and institutional strengthening of local health systems**, primary health care (PHC), the creation of effective, sustainable and efficient policies and their solidarity financing and the inclusion of health in all policies, as a universal right.

THE VALUES OF BEYOND SUNCARE

COMMITMENT to institutional strengthening

We work hand in hand with the main national and local authorities in all the countries in which we are present. Least developed countries in sub-Saharan Africa that need a commitment from us. As holders of obligations, they are key actors in all our proposals, always getting involved in the decision-making processes related to the projects of which they are part. In this way, all our actions are planned in the medium and long term, seeking to respect at all times the principles of institutional, socio-economic and cultural sustainability, harmonization with other international actors and donors present in the territories of action and alignment with public policies on health, gender (among others) of the countries of intervention.

STAKE

All our actions in the field of development cooperation are developed in a participatory manner, involving the beneficiaries, local organizations and local institutions, in the processes of change of their own territory, seeking at all times to consolidate optimal levels of appropriation in the beneficiary population.

PROFESSIONALISM

We use the knowledge and experience of not only national but also local people, professional experts from our sectors of intervention, which gives us the necessary agility to resolve in time any problem that may arise. and adapt to the changing reality of the countries in which we work.

SUSTAINABILITY

In the sense of permanence of the results achieved with the execution of our projects once the external donation processes, both public and private, are completed. The sustainability of our interventions is present in all its dimensions: institutional, socio-cultural, economic and environmental.

TRANSPARENCY

In all the processes undertaken from the identification to the evaluation of our interventions, and before all participating actors: donors, local counterparts, beneficiary population and society in general. All our projects include actions linked to the assessment of results (systematic analysis of indicators that help decision-making based on results) and accountability (external evaluation and audit).

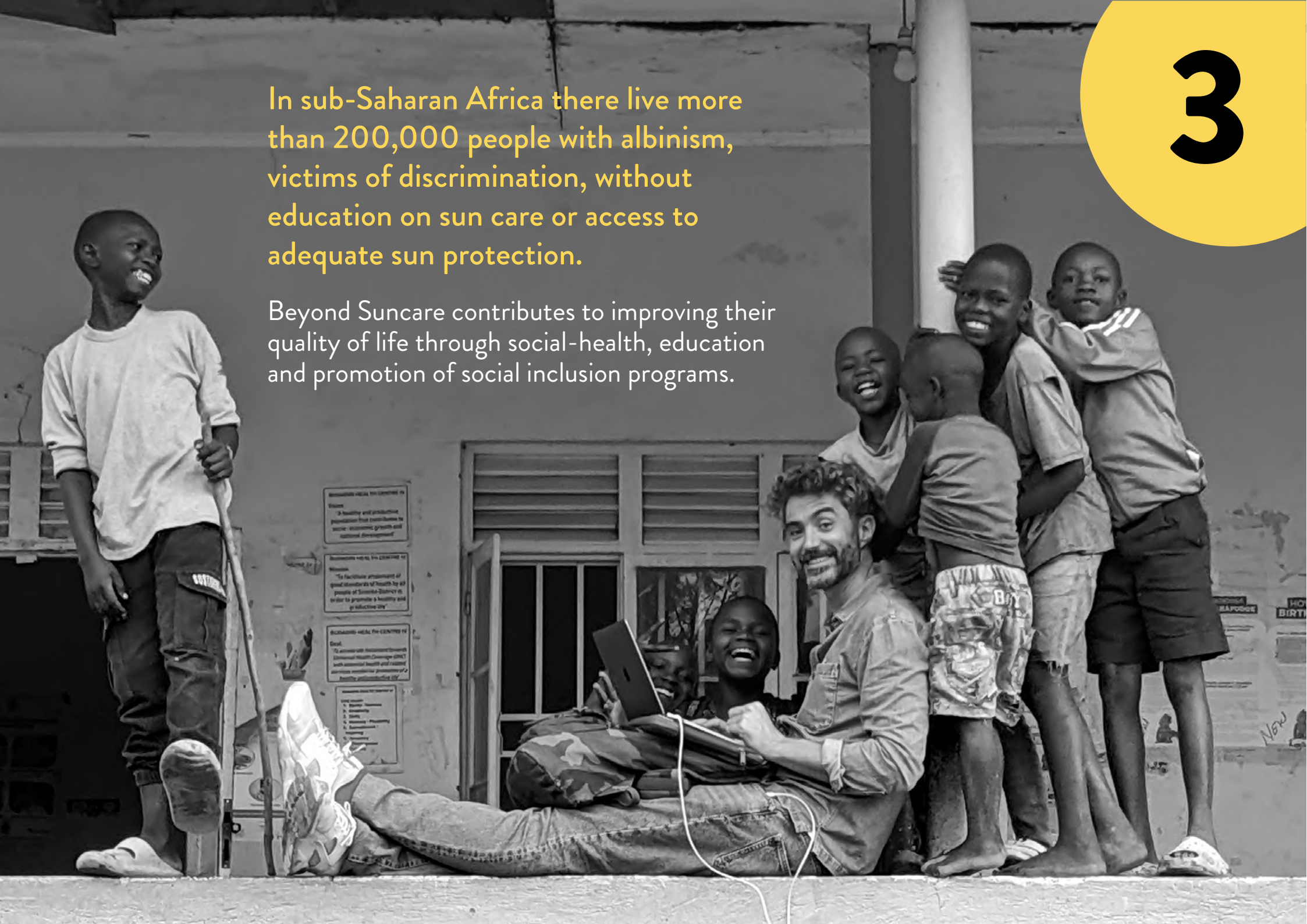


DATE OF VISIT: / /
SUN-RELATED LESIONS
Please report below your observations:
Sunscreen use (y/n)
Clothing protection (y/n)
Erythema (y/n)
Actinic Keratosis (y/n)
Sunscreen use (y/n)
Clothing protection (y/n)
Erythema (y/n)
Actinic Keratosis (y/n)



In sub-Saharan Africa there live more than 200,000 people with albinism, victims of discrimination, without education on sun care or access to adequate sun protection.

Beyond Suncare contributes to improving their quality of life through social-health, education and promotion of social inclusion programs.



PROBLEM

Albinism is not understood in African societies. Myths and superstitions surrounding the condition lead to **abandonment at birth and violence**. People with albinism (PWA) are **unlikely to receive education due to stigma**, fear and lack of safety mechanisms in schools. They usually end up earning a living through **low-paid, manual outdoor jobs**.

The health consequences of the combination of **high levels of UV radiation** and prolonged periods outdoors are very serious among PWA. In Tanzania, where stigma is deep-rooted, **only 1 in 10 lives beyond the age of 30**.

The **supply of sunscreen is very scarce throughout Africa**, most health centers do not have a supply, nor do they offer advice on sun protection to PWA. Albinism is also not included in health programs.

Beyond Suncare is the leading organization fighting for the right to health among People with Albinism in sub-Saharan Africa. We work with local communities to design innovative and sustainable projects to change the lives of people with albinism, especially those at highest risk of exclusion.

We build bridges, bringing together organizations and professionals from different fields to ensure **comprehensive and increasing solutions that lead to a systemic change**.

Beyond Suncare **promotes the integration of people with albinism into society** through dignified care that helps raise their self-esteem and fend for themselves.

We advocate politically and work hand in hand with the main national and local authorities and civil society organizations in all the countries in which we are present.

THE SOLUTION

OUR WORTH

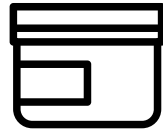
At Beyond Suncare we are committed to the institutional strengthening of the public health systems where we work, through the acquisition of equipment and the training of medical-health personnel.

- **Work with national and local institutions** and organizations specialized in albinism to find sustainable solutions.
- **The education** provided helps clarify the false beliefs surrounding albinism.
- **Intercultural approach:** appropriation-participation of the program by the beneficiaries and their communities.

- **Training: training and empowerment** of health and parasanitary personnel, and civil society organizations working on albinism to lead the projects.
We work with them, not for them.
- The formula of the **sun cream that we distribute is specifically adapted to the skin, reality and needs of the PWAs** of sub-Saharan Africa.
- Adherence to **treatment is monitored, addressing compliance challenges.**



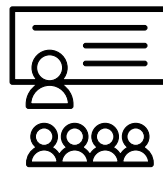
Education
and awareness



Prevention
and treatment
of skin cancer



Political advocacy
and institutional
strengthening



Training and
empowerment







“ I have come to learn how I have to take care of my daughter so that her skin is as healthy as possible.

Emily Patrick, 18 years old — attends the Santhe Health Center, in Kasungu district (Malawi), with her one-year-old daughter Promise



The new Plan will mark our path in a firm commitment to greater professionalization of our actions and greater transparency, exchange and improvement of relationships with other public and private actors, generating alliances and synergies to enable networking

VISSION.

Creating Awareness Of the
Right of (PWB's)

MISSION- Improve the L: alibood of Person
With Physical Disability

PREPARATION OF THE 1st STRATEGIC PLAN

In 2022, the [1st Beyond Suncare Strategic Plan](#) was prepared, product of an in-depth study, both of the African and international context, and of an internal examination of the strengths, specialties and capabilities of our entity. This analysis and planning effort aims to achieve greater impact, efficiency and effectiveness of Beyond Suncare's cooperation work, so that it contributes, to the greatest extent, to the achievement of human, equitable and sustainable development of all those African countries in those in which the entity carries out its international development cooperation work.

The new Strategic Plan is formulated to be useful in the actions to be undertaken in the coming years (2023-2027), incorporating the objectives that we want to achieve in each of the areas in which we work.

We believe in planning as the way to improve both the quality of our actions, as well as the rigor and transparency in its management and to develop our work in alignment with the main planning instruments of the European, Spanish and international development cooperation policy. of those Autonomous Communities in which Beyond has a Delegation

This Strategic Plan is, therefore, the product of the joint effort of all the people who are part of Beyond Sun-care. Its preparation has raised a debate on the entity's guidelines in the future and has enabled important reflections on the objectives and actions necessary to achieve the set goals.



READ IT HERE



WE ALIGN WITH THE SDGs

Aligned with the Sustainable Development 2030 Agenda of the United Nations and its principle of “LEAVE NO ONE BEHIND”, in 2022 our work has contributed to addressing the following Sustainable Development Goals.

3 GOOD HEALTH AND WELL-BEING



Ensuring **healthy lives and promoting well-being at all ages** is essential for sustainable development.

4 QUALITY EDUCATION



Education enables upward socio-economic mobility and is **key to getting out of poverty**.

5 GENDER EQUALITY



Empowering women and promoting gender equality is **critical to accelerate sustainable development**.

Inclusive and sustained economic growth can drive progress, create decent jobs for all **and improve living standards**.

8 TRABAJO DECENTE Y CRECIMIENTO ECONÓMICO



Reducing inequalities and ensuring that no one is left behind is an integral part of achieving Sustainable Development Goals.

10 REDUCED INEQUALITY



The SDGs can only be achieved with **strong global partnerships and cooperation**.

17 PARTNERSHIP FOR THE GOALS



SDG GOALS ON WHICH WE IMPACT



Target 3.8

Achieve health coverage including financial risk protection, access to quality essential health services and access to safe, effective, quality and affordable medicines and vaccines for all.

Target 3.b

Support research activities and development of vaccines and drugs for communicable and non-communicable diseases that primarily affect developing countries and facilitate access to essential drugs and vaccines.

Target 3.c

Substantially increase funding for health and the recruitment, development, training and retention of the health workforce in developing countries.



Target 4.1

Ensuring that all girls and all children complete primary and secondary education, which must be free, equitable and of quality.

Target 4.2

By 2030, ensure that all girls and boys have access to early childhood care and development quality preschool education.

Target 4.3

Ensure equal access for all men and women to quality technical, professional and higher education, including university education.

Target 4.4

Substantially increase the number of young people and adults who have the necessary skills, in particular, technical and professional, to access employment, decent work and entrepreneurship.

Target 4.5

By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and training.



Target 5.1

End all ways of discrimination against all women and girls around the world.

Target 5.2

Eliminate all forms of violence against women and girls in the public and private spheres, including trafficking, sexual and other types of exploitation.

Target 5.5

Ensure full participation and empowerment of women and equal opportunities for leadership at all decision-making levels in political life, economics and public affairs.

Target 5.c

Pass and strengthen sound policies and enforceable laws to promote gender equality and the empowerment of all women and girls at all levels.







Target 8.3

Promote policies aimed at development that support the activities productive activities, the creation of decent jobs, entrepreneurship, creativity and innovation.

Target 8.5

By 2030, achieve full and productive employment and decent work for all women and men, including youth and persons with disabilities, as well as equal pay for work of equal value.

Target 8.6

By 2030, significantly reduce the proportion of young people who are not employed and are not in education or training.

Target 8.7

Take immediate and effective measures to eradicate forced labour, end contemporary forms of slavery and human trafficking and ensure the prohibition and elimination of the worst forms of child labour.



Target 10.2

Strengthen and promote social inclusion, economic and political of all people, Regardless of your age, gender, disability, race, ethnicity, origin, religion or economic situation or other condition.

Target 10.3

Guarantee equal opportunities and reduce inequality of outcomes, including eliminating the laws, policies and practices discriminatory and promoting legislation, appropriate policies and measures in this regard.



Target 17.6

Improve regional cooperation and international North-South, South-South and triangular in science, technology and innovation and access to these, and increase the exchange of knowledge in conditions mutually agreed upon.

Target 17.7

Promote the development of technologies ecologically concerned and their transference, disclosure and dissemination to developing countries on favorable terms, including concessional and preferential terms, as agreed by mutual agreement.

Target 17.17

Encourage and promote the formation of effective alliances in the areas of public, public-private and civil society, taking advantage of the experience and strategies for obtaining resources from alliances.

**OUR
TEAM**

6



BEYOND SUNCARE



COLLABORATORS



**ACTIVITIES
CARRIED OUT
IN 2022**



*Countries in which
we worked during
the year 2022*



MALAWI

Towards a holistic approach

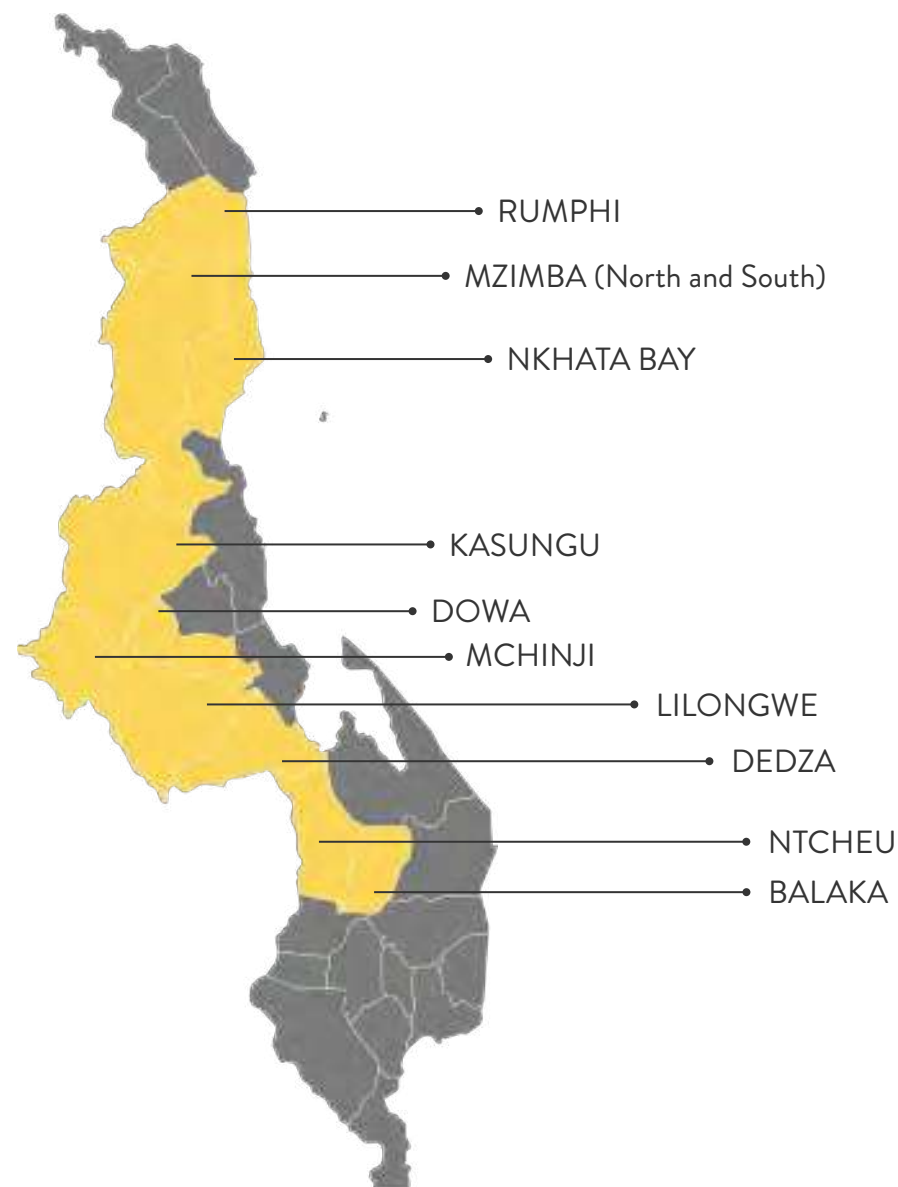
AREAS OF ACTION: INTERNATIONAL COOPERATION FOR DEVELOPMENT, INNOVATION AND SOCIAL RESEARCH, SOCIAL AWARENESS

THE CHALLENGE

In Malawi, as in most countries in sub-Saharan Africa, **skin cancer is the leading cause of death among people with albinism**, ending their lives at a very young age.

Albinism is not included in the training programs received by health professionals, which results in an overwhelming lack of knowledge of this genetic condition on the part of health professionals.

Poor diagnoses and treatments, inadequate health services, the inability to adequately treat skin diseases and the lack of prioritization of national health systems in the field of albinism and dermatology are some of the major problems. Challenges in countries like Malawi, which **only has two dermatologists and about thirty dermatology technicians in the entire country**. This explains the high incidence of skin cancer among people with albinism. Since 2017, Beyond Suncare has been working in the country in alliance with national and international actors, to combat this situation with a **focus on institutional strengthening and reinforcement of the structures and channels of the Ministry of Health**.





Together with the Malawi Ministry of Health, the Department of Dermatology at Kamuzu Central Hospital in Lilongwe and the Malawi Association of People with Albinism, Beyond Suncare trained 144 health workers in seven districts of the country in 2022.





**OUR MAIN ACTIVITIES ARE LOCATED IN MALAWI,
COUNTRY WHERE BEYOND SUNCARE IS OFFICIALLY REGISTERED
AS AN INTERNATIONAL NGO FOR DEVELOPMENT**

MALAWI

Towards a holistic approach

AREAS OF ACTION: INTERNATIONAL COOPERATION FOR DEVELOPMENT, INNOVATION AND SOCIAL RESEARCH, SOCIAL AWARENESS

BEYOND IN MALAWI

When, in 2020, Beyond Suncare launched its program “Improving the quality of life of people with albinism in Malawi: a strategy to prevent skin cancer and promote social inclusion”, it was essential to demonstrate the effectiveness of Beyond’s service package Suncare. For this reason, the program was implemented in the districts of Dedza, Ntcheu, Mzimba, Rumphu and Nkhatabay as a pilot project starting in August 2020.

Its good results and the good reception by local actors, both institutional and civil society, urged the expansion of the program to other districts in alliance with organizations such as the Ministry of Gender of Malawi and the National Association of People with Albinism of Malawi (APAM). The year ended with good news, since, together with the NGOs Yoneco (Malawi) and Standing Voice (England), and with the financing of the Malawi delegation of the European Union, we will implement throughout 2023 and 2024, an ambitious project that, among other actions, incorporates the specialized psycho-social aspect into our work.

We have been able to carry out our work in the country, in which we have our own office, thanks to the alliances formed with the Ministry of Gender and Health in Malawi, the British NGO Standing Voice and the financing of Africa Direct, the Colegio Medical Officer of Gipuzkoa, the Spanish Pediatric Foundation, the Spanish Association of Primary Care Pediatrics, the Casares City Council and other collaborators. To all of them it is our deepest gratitude.



“By the end of 2022, the customized UMOZI MAX sunscreen was distributed in 22 of the country’s 29 districts where 2,314 people with albinism are receiving regular dermatological support. 58% are children.

MALAWI

CUSTOMIZED CREAMS AND STRATEGIC ALLIANCES

In late 2022, Beyond Suncare **distributed UMOZI MAX in 22 of the 29 districts of the country** where 2,314 people with albinism are receiving regular dermatological support. 58% of these people with albinism are children.

Beyond Suncare continues to work to **make local production of UMOZI MAX a reality**. In addition, different potential donors have shown interest in purchasing our sunscreens for PWA and APAM has recommended UMOZI MAX to UNICEF and the Central Medical Stores Trust, the agency responsible for the acquisition of essential medicines and their subsequent supply to hospitals and health centers.

One of the main advances in 2022 at the level of institutional strengthening has been the signing of **an official collaboration agreement between the Ministry of Health and Beyond Suncare** that regulates and promotes joint actions.

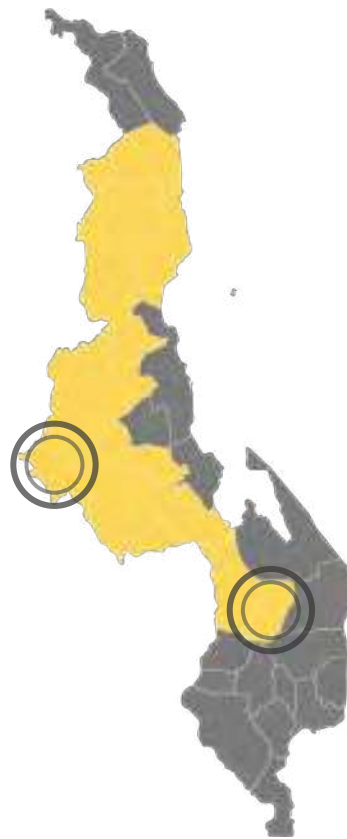


EXPANSION TO TWO NEW DISTRICTS

In 2022 our work was consolidated in the 9 districts we were in and expanded to two new ones: **Balaka and Mchinji**. The expansion of the actions began with a mapping to choose the appropriate health centers to carry out the clinics. Four health centers were chosen for each district selected under the following criteria: number of people with albinism in the area and the conditions of the facilities, for the greatest optimization of our services.

After the identification, the people with albinism in the area were mobilized, led by APAM (National Association of People with Albinism), to continue with the launch of the training and training of health personnel, responsible for leading the clinics that will be carried out quarterly or quarterly

As is our procedure, Malawian dermatologists from the dermatology service of the Lilongwe Central Hospital were responsible for the training in collaboration with the local Beyond Suncare and APAM team.



QUALITY CONTROL VISITS FOR CONTINUOUS IMPROVEMENT OF SERVICES

In 2022, eight quality control visits were carried out. These **periodic audits** are regularly carried out on the clinics with the **objective of measuring the impact of the project among the beneficiaries and evaluating the quality of the clinics**. Aspects such as whether health workers are managing services adequately are analyzed and evaluated, in addition to providing technical support wherever some deficiencies are observed.

The quality assurance teams consist of Beyond Suncare members on the ground, dermatologists from Kamuzu Central Hospital, as well as representatives from the APAM national and district office and the Ministry of Health. As is our procedure, Malawian dermatologists from the dermatology service of the Lilongwe Central Hospital were responsible for the training in collaboration with the local Beyond Suncare and APAM team.

The quality control visits in 2021 and 2022 showed that, although the healthcare personnel responsible for the implementation of the clinics are doing a good job, they still needed to improve their knowledge and skills in the identification of lesions or other forms of malignant neoplasms. -nas. To this end, it was suggested to carry out support training that will be carried out in the first half of 2023. In the quality control visits we also saw that among the beneficiaries it is important to improve participation and sun protection habits. In addition, there is a perceived need to expand the program to the entire district, covering the most remote areas, so as not to leave anyone behind.

MALAWI

TRAINING REINFORCEMENT

Reinforcement training sessions were conducted in Dedza and Ntcheu in April, and in Kasungu and Dowa in October.

Health workers from the centers where Beyond Suncare began working in 2020 were invited to participate. Three health workers from each health center, five from the district hospital and the district APAM and Macoha coordinator. In total 65 participants in Ntcheu, 16 in Dedza, 17 in Kasungu and 15 in Dowa.

The goal of these trainings is to reinforce the challenges we saw during our quality control supervision visits and the use of monitoring materials.

“THE IMPORTANCE OF SANITARY TRAINING LOCAL IN MALAWI”

INTERVIEW WITH MALAWIAN PHARMACIST ELIAS JAMBO



MANAGEMENT OF IDENTIFIED PATIENTS WITH SKIN CANCER

In 2022, pre-cancerous or cancerous lesions were identified in **50 patients** and had to be referred to central hospitals.

Beyond Suncare continues to collaborate with the Spanish NGO Dermalawi, which travels regularly to Malawi, and refers patients who cannot be treated locally.

In 2022, Dermalawi made 3 trips to Malawi, in February, June and October. Tumaini, an Austrian NGO made up of dermatologists, also travels to Malawi to provide dermatological services and Beyond Suncare also refers patients to them. Additionally, in 2022 Standing Voice organized a surgery camp in November where one of the patients was referred. In the districts where Standing Voice works, minor surgeries are done in the same area. district.

Of the 50 patients, 41 have been treated; 21 have been cured, 17 are awaiting results or additional treatments, and 3 are in palliative care. Of the remaining 9, 6 are waiting to be treated and 3 cannot be reached. One of our goals for 2023 is to strengthen the referral system and management of skin cancer at regional and local levels.

“

According to international institutions such as the FAO, 85% of Malawi's population lives in rural areas and more than 90% of dermatological services are located in urban hospitals. For these reasons, the training of health workers in rural areas is very important.

BEYOND
SUNCARE

TOGETHER WE CAN PREVENT SKIN CANCER



OUR SERVICES

Providing education on skin care to persons with albinism and care takers.

Empowering health workers through capacity building trainings in sun protection and skin care.

Ensuring constant availability and access to high quality and tailor-made sunscreen products to persons with albinism in Malawi.





“

Thanks to community theater performances, 3,500 community members received messages aimed at understanding albinism, photo-protection and the need to join forces in the protection and care of people with albinism.

COMMUNITY SENSITIZATION

Likewise, in line with Beyond SunCare's strategy of reinforcing its community awareness and sensitization actions, we began to work with community theater groups, which designed the script for a specific performance with the support of BSC on the understanding of albinism. These dramas were organized in 6 districts, Dedza, Ntcheu, Rumphu, Nkhatabay, Mzimba South and Mzimba North. Around 3,500 people attend these events.

The interventions are intended to promote safety, visibility, improved self-esteem and healthy lifestyles among people with albinism.

The messages transmitted to communities in general include: understanding of albinism, photoprotection and the need to join forces for the protection and care of people with albinism.

At the end of the theatrical performance, volunteers were asked to go on stage and explain to the audience what they had learned. Local media through the **Nation** newspaper published an article on Beyond SunCare's positive approach worth emulating to promote the improvement of living conditions among people with albinism.



INTERNATIONAL AWARENESS DAY OF ALBINISM

On December 18, 2014, the United Nations General Assembly adopted resolution A/RES/69/1970 proclaiming that, starting in 2015, International Albinism Awareness Day will be celebrated on June 13.

In Malawi, different events were held for Albinism Awareness Day. The first in Lilongwe on June 9 organized by MHRRRC, and the official event organized by the Ministry of Gender in conjunction with different organizations was held in Blantyre on June 13 and 14.

Beyond SunCare was present at these events to make its work known among the community and public organizations and do its part so that albinism is understood in society, contributing to ending all types of discrimination.



MALAWI

OUR WORK IN MALAWI

IN FIGURES



209 Holistic clinics in rural and semi-urban areas



50% of people with albinism attended are **WOMEN**



16% Reduction in injuries associated with the development of skin cancer



2.314 People with albinism beneficiaries of services



58% of people with albinism attended are **MINOR**



76% Feel their self-confidence reinforced



144 Health personnel trained and empowered to manage clinics



41 People with skin cancer treated



98% Recommend the program and sunscreen



Dr Esther Mzumara, head of the Department of Dermatology at Kamuzu Central Hospital, is one of two dermatologists working in Malawi, with a population of 20 million.

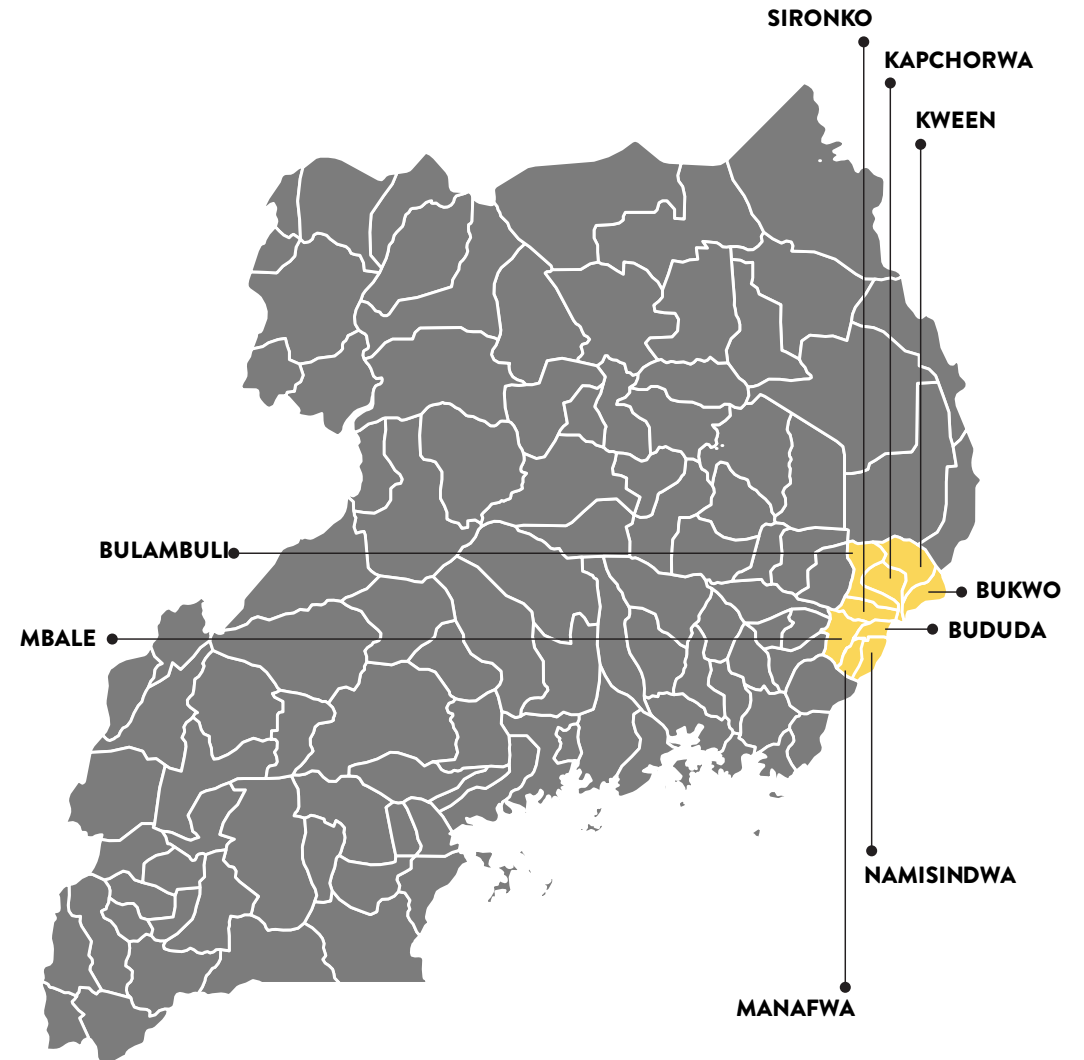
UGANDA

We start a project in the Pearl of Africa

AREAS OF ACTION: INTERNATIONAL COOPERATION FOR DEVELOPMENT, INNOVATION AND SOCIAL RESEARCH, SOCIAL AWARENESS

THE CHALLENGE

Vulnerable to discrimination and premature death from skin cancer, people with albinism (PWA) are among the most marginalized in Uganda. However, the government and civil society do not take them into account. In Uganda, **the eastern Bugisu sub-region has the highest number of PWAs in the country.** In this particular sub-region there is very little knowledge about albinism, being a mountainous and difficult to access region affected by chronic poverty, access and penetration of information is complicated. Additionally, there is much concern about the absence of government-led programs and initiatives to ensure that PWAs have access to vital supplies such as sunscreen and healthcare.



BEYOND SUNCARE IN UGANDA

Following Beyond Suncare's strategy of expanding its services in different countries in Sub-Saharan Africa, Beyond Suncare had the opportunity to learn about the work that Source of the Nile Union for Persons with Albinism (SNUPA) is doing in Uganda and the possibility of starting a collaboration to expand your project. With the support of the British NGO Advantage Africa, since 2016 SNUPA has been running a comprehensive advocacy project for this group, holding regular dermatological clinics in the neighboring Busoga sub-region. 6 years of this ongoing intervention have dramatically improved the skin condition of 800 people with albinism, with skin cancer cases decreasing by 70%.

On the other hand, Kampala-based civil society organization Albinism Umbrella (AU) unsuccessfully attempted to open a sunscreen production unit in Kampala. Beyond Suncare also wanted to evaluate the possibility of supporting Albinism Umbrella to resume this initiative.

Therefore, in March 2022, Beyond Suncare carried out an **evaluation mission** in the country with the objective of analyzing the work that SNU-PA is doing and the possibility of expanding to another region, in addition to better understanding the supply system. of sunscreen for people with albinism in the country with a focus on evaluating the possibility of launching a local production unit with Albinism Umbrella.

With a positive result from this evaluation mission, the project in collaboration with SNUPA was launched on July 22 in the Bugisu sub-region. This project seeks to reduce the incidence of skin cancer among people with albinism in the Bugisu sub-region, emphasizing the education and training of 80 health workers on albinism and skin cancer prevention, generating awareness of albinism among people albino individuals and their caregivers, and the promotion of self-care with the use of sun protection materials.

Our work in Uganda is possible thanks to the great support of the British Croda Foundation, the Africa Direct Foundation and the support of collaborators who, as in other countries, collaborate with donations in kind and who are BASF, RNB, Saqueim, Parafina and Zurko Research.

Below, we detail in more detail the activities carried out in the country in 2022:

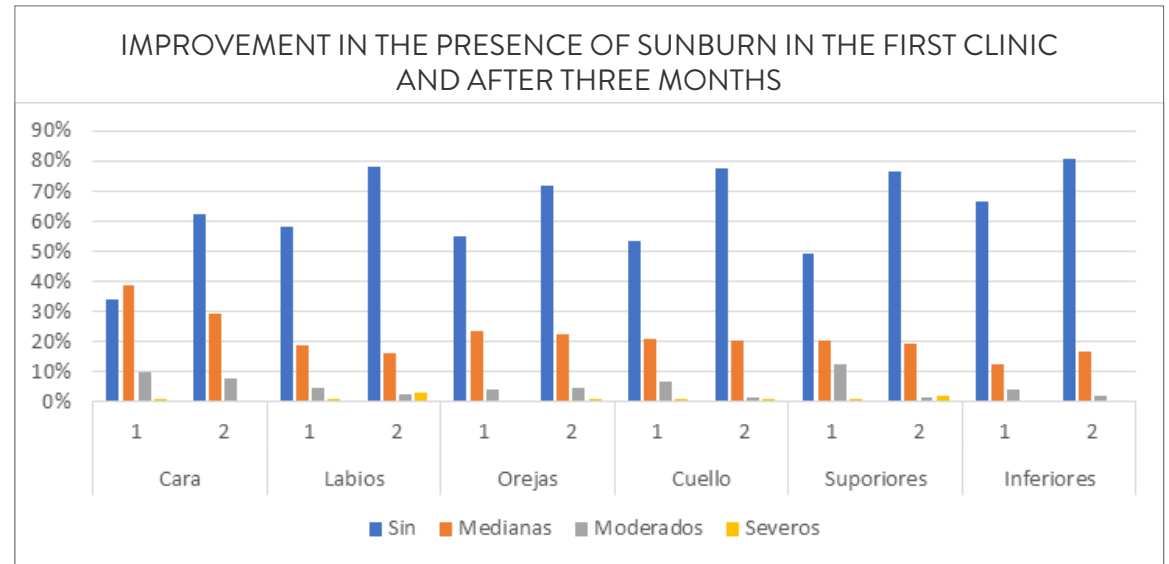
- **Acquisition and shipment of personalized UMOZI MAX sunscreens, lipsticks with SPF and hats.**
- **Implementation of quarterly dermatological clinics** in 9 rural and semi-urban health centers of the government network.
- **Training and training of local healthcare personnel** from the 9 health centers since they are in charge of supporting the clinics implemented in their health establishments. These trainings are aimed at doctors, senior health officials, public health workers and nurses.
- **Carrying out a feasibility mission**, to evaluate the establishment of a sun protection production unit in Uganda.



UGANDA

In less than 12 MONTHS we obtained the following results:

- ▶ **294** People with albinism treated
- ▶ **61%** Of people with albinism attended are MINORS
- ▶ **74%** Improved use of sunscreen
- ▶ **80** Health workers trained to provide primary care services in dermatology
- ▶ **31%** Improving knowledge about albinism amongst health workers
- ▶ **22%** Improvement in the presentation of sun damage on the skin



IDENTIFICATION MISSION FOR THE POTENTIAL ESTABLISHMENT OF A SUNSCREEN PRODUCTION UNIT IN UGANDA

The mission was carried out in Kampala in collaboration with Albinism Umbrella. During the trip, the evaluation team held meetings and interviews with stakeholders from various backgrounds and areas of expertise.

ACCESS TO SUNSCREEN

It was evident that there is no availability of sunscreen, the Government does not purchase sunscreen, so it is not present in Health Establishments. Consequently, access is limited to sporadic and private donations. Sunscreens have recently been declared essential medicines and are expected to be imported duty-free in the coming months. However, public procurement is not yet underway. There have been two attempts to launch a production, but they failed for many reasons; among them are poor cosmetic elegance and poor acceptance by users

LOCAL REGULATIONS

There are no policies that support PWAs, although the government appears to be open to helping the PWA community. Albinism falls under the Ministry of Gender. They also have important support from different organizations of people with disabilities such as unions and CSOs, and their voices are heard in the government, although the proactivity and allocation of public media and resources is very discreet. By the end of the year, Uganda had a final draft of the National Action Plan for Persons with Albinism in Uganda which was expected to be presented to the Government promptly. The next step, which would take place throughout the year 2023, would be to make official whether or not the Government of Uganda finally adopts the NAP



UGANDA

IDENTIFICATION MISSION FOR THE POTENTIAL ESTABLISHMENT OF A PHOTOPROTECTIVE PRODUCTION UNIT IN UGANDA

CONCLUSIONS OF THE MISSION AFTER THE MEETING WITH INSTITUTIONS AND MULTILATERAL ORGANIZATIONS AND NGOS

During the trip, the evaluation team held meetings and interviews with stakeholders from various backgrounds and areas of expertise, including:

- Ministry of Health: Meeting with Dr. Upenyho D., from the Department of Community Health that depends on the Ministry of Health and with those responsible for Disability and rehabilitation.
- National Council on Disability (NCD): Meeting with Beatrice Guzu – executive secretary
- National Union of Disabled Persons in Uganda (NUDIPU): Meeting with Esther Kyoziira – executive director
- United Nations Human Rights (UNHR): Meeting with Ulrike Kahbila and Epodoi Florence – National HR Officers
- Open Society Foundations - Meeting with Frederick Ouko – Official of SOIEA Programs and Geoffrey Katende – Disability Rights and Rural Role in Uganda



Beyond Suncare believes that it is feasible and advisable to establish a production unit in Uganda because there is a great need on the part of the target population and the availability of these essential items is almost non-existent, limited to donations or procurement of unaffordable imported commercial products, sunscreens that do not always guarantee effectiveness or safety. Furthermore, the lack of competitors and the support promised by many stakeholders and allies in different fields play in its favor.

However, there is still much work to be done as the path forward is unclear; the scope, type of products and business model, and the entire process is yet to be defined. Furthermore, the uncertainty of who will pay for the final product (sunscreens) is one of the main challenges and can compromise the sustainability of the initiative. However, BSC does not doubt the capabilities of Albinism Umbrella due to its legacy, diligence and proactiveness, and knows that this will become clear soon.

Furthermore, BSC has a lot of experience, strong international partners and consolidated know-how that it will gladly put at the disposal of AU in its commitment to contribute to the start-up of the operations of the local productive unit; once the business model is clear.

BSC also sees the great opportunity and believes that this is a good time to launch this project; The National Albinism Plan was introduced in Uganda and sunscreens have also been declared essential and duty-free medicines. Therefore, the momentum must be seized. Finally, donors and stakeholders seem ready to support.



DISCOVER THE START OF OUR PROJECT
IN UGANDA IN **1 MINUTE**

“

Jimmy Mkwapatira, is a health technician at the Kayembe Health Center in Dowa district. People with albinism, especially in rural areas, lack information about their genetic condition.

In the clinics, health workers like Jimmy organize a first meeting to explain what albinism is, clarifying concepts about this genetic condition, normalizing the condition, promoting self-care measures, teaching how to apply sunscreen to prevent skin cancer and pointing out the importance of going to clinics every four months for dermatological follow-up.





ABANTJA LA MTSI... ADZABWELA
MADOKOTALA - A... DOWA
ADZABWERA... OCTOBER 2021

Zaka Zitalu
Mpaka Zisanu
Opanda Nkhawa

Keep this window open



RWANDA

We consolidate actions in the country

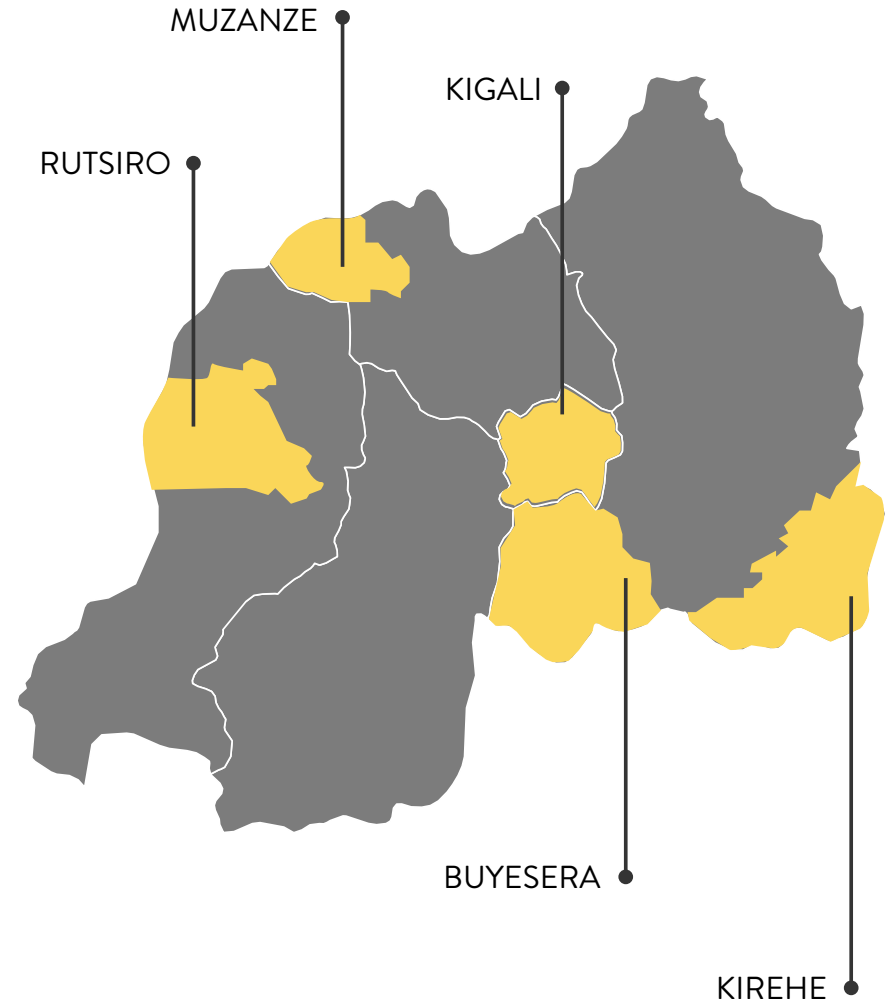
AREAS OF ACTION: INTERNATIONAL COOPERATION TO DEVELOPMENT, SOCIAL AWARENESS

WE REINFORCE OUR ACTIONS IN RWANDA

EXPANSION OF THE PROJECT TO NEW DISTRICTS AND FOCUS ON INSTITUTIONAL STRENGTHENING

Our project in Rwanda aims to reduce the incidence of skin cancer among people with albinism, in addition to training health workers about albinism and skin cancer prevention, generating knowledge about albinism among PWA and their caregivers, promoting self-care measures, increasing the use of sun protection materials and referring cases identified with advanced cancer for operations. The project also analyzes the current situation of sun protection services for PWAs in Rwanda, in particular access to high-quality sunscreens to evaluate the feasibility of establishing, in a second phase of the project, high-quality local production of quality and affordable sunscreens.

Health Alert Organization (HAO) is responsible for implementing the project on the ground. Founded since October 2016, HAO is an organization that works with the aim of unifying the efforts of health professionals to raise awareness and advocate for the prevention and control of risk factors for NCDs, malnutrition, mental health and albinism through information programs. HAO is made up of health professionals from various fields including dermatology officers, public health officers, nurses and mental health officers. They also have members who are not health professionals, including accountants and IT professionals.



The project began with the purpose of identifying people with albinism; Learn more about the problems they face and help them move forward with better health. It began in 2017 serving a group of PWAs in Kigali that depended on a small fund from the monthly contribution of members of the organization.

In 2022, HAO expanded its actions to 2 more districts, covering 7 of the 30 in the country and thanks to the support of Beyond, it gave its strategy a more sustainable focus with the incorporation of actions aimed at institutional strengthening with an eye toward training of nurses from 3 of the 7 districts.

Likewise, in March 2022, Beyond Suncare carried out an evaluation mission in the country with the objective of analyzing the work that HAO is doing and the possibility of expanding to other districts in the country, in addition to better understanding the sunscreen supply system for people with albinism in the country, and to evaluate the possibility of launching a local production unit



RWANDA

We consolidate actions in the country

EVALUATION MISSION BY THE HEADQUARTERS TEAM

In March 2022, Beyond Suncare carried out an assessment mission to Rwanda with the aim of analyzing and evaluating the work being carried out by the counterpart Health Alert Organization on the ground, in addition to better understanding the current system of access to health services, especially access to skin cancer prevention services and sun creams for people with albinism in the country.

Below are some observations extracted from the visit with a focus on the analysis of the country's context and the viability of continuing to explore the possibility of local production of sun creams:



LACK OF PROVISION OF DERMATOLOGICAL SERVICES

PWAs in Rwanda do not have regular access to photo protection services and dermatological follow-up; Dermatological services are only accessible in the capital Kigali. For PWAs living in rural areas, the only way to receive this service is through the clinics run by HAO, which currently only offers its services in 7 districts of the 27 that exist in Rwanda. Likewise, economic challenges mean that many cancer patients take months before raising the money necessary to pay for surgical interventions. If not, they have a waiting list of up to 6 months to be served.

LACK OF TIMELY SUPPLY AND CONSTANT OF SUN CREAM

In the same way as with services, the supply of creams depends on the clinics organized by HAO. Although sunscreens are considered essential medication in Rwanda and the government should provide them to all health centers, there are still many PWAs who cannot find the creams in their health centers. This is because health centers lack reliable records with the number of people registered at the center, necessary before placing the order.

LACK OF AWARENESS ABOUT PHOTO PROTECTION AND USES OF SUN CREAM

Although dermatological services, receipt of creams and education come from health professionals, there is a lack of awareness and good education on the understanding of albinism, photoprotection and the use of creams, since the staff of health is not trained in this area.

CHALLENGES IN SOCIAL INCLUSION AND INTEGRATION OF PEOPLE WITH ALBINISM

Misinformation around albinism is widespread and affects all sectors of society. The prejudices surrounding the condition do not allow full inclusion of PWA in the country, causing them to not have the same job or schooling opportunities as their colleagues without albinism. Good awareness is necessary that covers all layers and strata of society, which makes it clear that PWAs have the same capabilities and that they must be accepted and included like the rest of the individuals.

LACK OF A NATIONAL PLAN ABOUT ALBINISM

In Rwanda there is no national plan to support people with albinism in the country. The government does not prioritize the problems that people with albinism suffer daily.

FEASIBILITY OF THE ESTABLISHMENT OF A SUNSCREEN PRODUCTION UNIT IN RWANDA

HAO has had several meetings with the ministry of health about the possibility of establishing a sun cream production unit in Rwanda, and is awaiting our application for approval to establish the local Formulation Unit. Musanze district has transferred land for the production unit. Sun creams were declared drug shortages in 2018 and the government has begun to buy sunscreens, although these still do not reach all centers of Rwanda. There is a local preference policy by the government, where the government gives priority to local manufacturers.

The Ministry of Health said that once the creams are produced locally, an agreement will be signed to supply them to all health centers in Rwanda.

At Beyond Suncare we will continue to delve into the viability of moving forward with this initiative.



RWANDA

RESULTS OBTAINED IN RWANDA IN 2022:

- ▶ **495** People with albinism attended
- ▶ **53%** Of people with albinism attended are MINORS
- ▶ **48** Trained nurses
- ▶ **40%** Improvement of knowledge about albinism amongst health workers





DEMOCRATIC REPUBLIC OF CONGO

WE STARTED OUR PROJECT IN DRC

AREAS OF ACTION: INTERNATIONAL COOPERATION TO DEVELOPMENT, SOCIAL AWARENESS

BACKGROUND AND DESCRIPTION OF ACTIONS

The Democratic Republic of the Congo (DRC) is a country in sub-Saharan Africa that, although it does not have reliable statistics, has a high number of people with albinism according to clinical observations and scientific publications carried out in this country. Taking into account the current population of the DRC (92,377,986 inhabitants), it is estimated that there are +18,000 people with albinism established in the 24 provinces of the DRC in 2022, predominantly in the KASAI and TSHOPO regions where consanguineous marriages are frequent according to anthropological data from the DRC. KINSHASA is also affected because, being the capital of the country, with the migration of the population from the provinces to the capital, it registers numerous cases of albinism according to the observations and records of civil society organizations.

Although there is no national policy on the management of problems related to albinism in the DRC, some non-governmental organizations have developed actions to address some of these problems.



This is the case of CORBETTA RDC; a Non-Governmental Organization with national scope that, after having witnessed the death of several PWAs due to skin cancer in the DRC, launched with its own funds a program to combat skin cancer with preventive and very limited and available curatives that, however, have made it possible to drastically reduce morbidity and mortality linked to skin cancers in Kisangani (TSHOPO) since 2014; program that has also been developing since 2021 in KINSHASA; 2022 in Mbuji-Mayi (KASAI) and soon in Lubumbashi (KATANGA). Throughout the DRC, access to sun protection creams is very limited, not only due to the scarcity of these precious products in the country, but above all because of the very exorbitant sales price for a largely poor population. . In addition, commercially available creams are usually not suitable for the skin of people with albinism in sub-Saharan Africa, according to observations of those who apply them and specialists in the country.

At the end of 2021, the CORBETTA RDC Association, and Beyond Suncare's counterpart on the ground, signed an MoU to support the association with sun creams and educational materials as well as regular advice.



IN 2022 THROUGH THIS COLLABORATION THE FOLLOWING GOALS WERE ACHIEVED:

▷ **550**
People with albinism treated

▷ **3**
Trained nurses

▷ **37**
People with albinism could get surgeries

▷ **40%**
Improvement of knowledge on albinism amongst health workers



**OTHER
OUTSTANDING
ACTIONS**

WOMEN4CHANGE



Gioseppe and the Esperanza Pertusa Foundation created the Women4Change charity sandals for the SS23 season. This collection was completed with a bracelet made with the same beads by hand. All profits from the sale of the bracelets and the two models of sandals will be donated to Beyond Suncare at the end of 2023. All our gratitude to the Esperanza Pertusa and Gioseppe Foundation for their support and enthusiasm for the program.

Esperanza Pertusa decided to recognize Mafalda Soto, co-founder of the NGO Beyond Suncare, as the protagonist of its Women4Change transformative leadership program. The program recognizes in Mafalda Soto the values and trajectory of a transformational leader. Her person, her team and the entity that she has created and directs share with the **Esperanza Pertusa Foundation and the Woman4Change** program the necessary values of leadership that promotes positive social transformation.

Mafalda Soto's career as a leader, resistant over time, working in a very difficult environment, generating diverse and highly committed teams, causing a positive social impact, working every day to combat poverty and discrimination, to the promotion of the health and well-being of people with serious difficulties reflects the values that the Women4Change leadership program aims to highlight and disseminate.

The Women4Change program granted Beyond Suncare a financial endowment, spread over two years and launched two solidarity actions.



UMOA IS BORN: NATURAL COSMETICS WITH PURPOSE



In December **UMOA** was born, a line of 99% natural cosmetics that is born from the will to continue breaking down invisible walls and improve the quality of life of the group of people with albinism for which Beyond Suncare has been fighting since its birth as an organization. UMOA is defined as a line of cosmetics with a purpose, created from natural formulas that reinforce defenses without altering the balance of the microbiome and that allocates 10% of its profits to Beyond Suncare.

This social initiative, promoted by the founding team of Beyond Suncare, adds to the belief that improving the world is possible thanks to the set of small steps of many people together. UMOA prioritizes ingredients harvested in a sustainable and environmentally friendly way, uses recyclable packaging and 100% cardboard and paper from responsibly managed forests.

In its manufacturing processes, it uses renewable energies for the electricity supply and reuses the water used in the manufacturing process. Finally, the brand entrusts the organization and management of the warehouse to ILUNION, a social business project promoted by an excellent human team, which is based on the principles and values of the ONCE Social Group.

Likewise, in 2022 Beyond Suncare also signed an agreement with the personalized cosmetics firm Uniliquely that will allocate 1% of its profits to the NGO.

2022

A YEAR OF CONSOLIDATION OF ALLIANCES

Si por algo destaca 2022 a nivel organizativo es por el protagonismo de la creación de nuevas alianzas con fundaciones, empresas europeas, instituciones y organizaciones de la sociedad civil de los países de África Subsahariana donde Beyond trabaja; así como la formalización de colaboraciones previas.

The agreement with the [Croda Foundation](#) stands out, our main support in Uganda, and [ROVI Laboratories](#) with their support of our work in Malawi. With the British NGO [Standing Voice](#), with whom we have been collaborating since our beginnings, we formalized a Memorandum of Understanding that establishes and regulates our cooperation in Malawi.

We also updated our collaboration with [RNB](#), leading Spanish cosmetic company that supports us in technical assistance and the manufacture of personalized sunscreens that we subsequently package in the local languages of the countries in which we operate and ship to Africa. Another novelty is the formalization of a Memorandum of Understanding with the [International University of La Rioja](#).

On the other hand, the agreements formalized with counterparts and local institutions stand out. In Uganda, we signed a framework agreement with the local NGO [Source of the Nile Union for Persons with Albinism](#) which is co-responsible for the implementation of our project in the country together with the local CSO Elgon Foundation for Persons with Albinism. Alliances were also formalized with another Uganda NGO, [Albinism Umbrella](#).

Finally, Beyond Suncare Malawi consolidated its collaboration with the health institutions with which it has been working closely since 2017 through the formalization of a Memorandum of Understanding with the [Ministry of Health](#). The purpose of this MoU is to provide a framework for cooperation and facilitate collaboration between the Parties. Both parties agree to cooperate through complementary and/or joint programming efforts that support the achievement of the objectives and results described in the III Strategic Plan. of the Health Sector, the National Action Plan on Persons with Albinism in Malawi and the Malawi National Disability Integration Strategy.



MALUKHU
HEALTH CENTRE III

INDUSTRIAL DIVISION
GOV'T AIDED

BEYOND
SUNCARE

BEYOND
SUNCARE



9

**COMMUNICATE
TO GO
FURTHER**



t Beyond we are committed to communication to make our work visible and ensure that many more people know our work with people with albinism in Africa, as well as the reality and challenges that surround them.






In 2022 we continue to expand our presence throughout the social media ecosystem by diversifying the content published and maintaining the pace of publication.

Likewise, thanks to the valuable support of our volunteers, we managed to enter the nonprofit Google Ad Grants program through which Google provides us with free advertising support for Google searches.

With sure steps, our notoriety on social networks has continued to consolidate on social networks, especially on the two networks that are most strategic to us, LinkedIn and Instagram.

JANUARY 2022

JANUARY 2023

	1019	1104
	1440	1660
	221	265
	290	730
	30	30

BEYOND SUNCARE IN THE MEDIA

Likewise, our work was made visible in numerous audiovisual, digital and paper media, from the newspaper [El País](#), to the reference magazine for cosmetic and personal care experts [HPC Today](#), a bimonthly magazine that addresses topics of personal care, cosmetics and dermatology and in which we present a scientific publication in collaboration with the German chemical company BASF

Also in Malawi, our work was made visible in the national newspaper, The Nation, which indicates our consolidation and the increase in notoriety of the NGO in the sub-Saharan country.

EL PAÍS

PLANETA FUTURO

DA MAZAL DEL ALBINISMO

Lodina, Jeremiah y Tumaini, tres personas con albinismo que me cambiaron la vida

En países como Malawi, los albinos están expuestos a riesgos tan diversos como el cáncer de piel y las agresiones por el estigma en torno a ellos. La directora de una ONG que fabrica cremas solares relata cómo trabajan para protegerles de todo peligro



Mafalda Soto (izq.) y Jeremiah y Tumaini (dcha.) en una sesión de lanzamiento de la campaña de Beyond Suncare en Malawi. Foto: Mafalda Soto

MALFALDA SOTO
Directora - 01 JAN 2022 - 08:40:00

f x in

On Saturday, the setting moved to Pakachere where artists such as Sangie, Quest

On Sunday, the last day of the event, music continued to take centre stage with

Clavé
Dj U
On perfo

‘A
‘b
HOW
Cook

One
urba
One
know
Battle
to p
Malin
Lilong
Satur
His
days
concert
poor
P o
Enter
Mlaka
Lilong
with
with d
M
and
Tuesd
on his
page:
nyse
ny ba
Mlaka
the Li
‘I
shoul
legend
Banda
The
also a
200 t
freely
want
Mlaka
The
of On

Part of the performances during the launch

NGO uses theatre to educate masses about albinism

PLEDGE JALI
STAFF REPORTER

Charitable organisation Beyond Suncare has embarked on a nationwide sensitisation campaign about albinism using drama and music.

The campaign seeks to improve awareness and understanding about albinism as well as promote visibility of persons with albinism among communities to prevent stigma, discrimination and persecution to people with the condition.

In an interview on Monday after launching the campaign at Gesha Market in Mzuzu, Beyond Suncare country manager

Devline Msowoya said people with albinism continue to face discrimination in the country due to knowledge gaps, hence rolling out the campaign to raise awareness.

“People with albinism still face persecution and discrimination because of information gap. We have, therefore, embarked on the awareness campaign to educate the masses that people living with albinism are equal human beings, only that their skin is different because they lack melanin,” he said.

Msowoya said they have partnered with Pace Theatre Company who will be conducting performances across the country along with music concerts whose artists will also feature persons with albinism.

“This will contribute to improved self-esteem towards improved lives among persons with albinism in Malawi,” he said.

Pace Theatre Company managing director Gibson Chisale said as artists they have a role to play in raising awareness through drama.

“We are happy to be part of the noble cause through the interactive drama. This information should go viral so that Malawians know the truth about albinism,” he said. ■

PHOTOGRAPH BY MAFALDA SOTO

SUN CARE

A safe and dignified life for people with albinism

MAFALDA SOTO VALDEZ** STEPHANIE ACHER*

*Corresponding author
1. Beyond Suncare, Malawi, Spain
2. BASF (Bentzen GmbH, Ditzsch-Wyhlen, Germany)

Abstract

Beyond Suncare is a Non-Governmental Organisation (NGO) that aims to protect people with albinism from skin cancer, discrimination and attacks. The NGO has a longstanding cooperation with BASF to develop and provide sunscreen that meets the specific challenges of people with albinism in the sub-Saharan region. The chemical company provides its expertise and ingredients free of charge. Together, Beyond Suncare and BASF have formulated an innovative sun care product that cuts the risk of skin cancer for vulnerable people. This is just one way that this initiative is improving quality of life, safety and dignity for people with albinism in Africa.

Keywords

- Albinism
- Africa
- Sun cancer
- Sun protection
- Education
- Health
- Sun care

HEALTH AND DIGNIFIED LIFE FOR PEOPLE WITH ALBINISM

More than 200,000 people live with albinism in Africa and the sub-Saharan region is home to more people with albinism than anywhere else in the world. For this group, protection from the sun is a matter of life and death: 9 out of 10 people with the condition die of skin cancer before the age of 30.

Beyond Suncare is a Non-Governmental Organisation (NGO) that is striving to ensure safety and dignity for people with albinism in Africa. The story of this NGO begins in 2009, when its two founders met, Mafalda Soto, a pharmacist specialised in tropical medicine and international health, was coordinating socio-sanitary projects to support vulnerable and excluded groups in Malawi. Lorea Bagatzpota, a dermatologist, was working with people with albinism in Tanzania and training African specialists to treat skin cancer in people with albinism. In 2016, the two co-founders established Beyond Suncare, together with a third co-founder, Rocio Diaz-Agero. The NGO aims to guarantee the right to health and dignified life for people with albinism in Africa. And BASF has been partnering with the founders of Beyond Suncare for more than a decade.

Mafalda Soto is now a United Nations Champion on Albinism, and Beyond Suncare was selected as a best practice example by the United Nations in 2017. Her first contact with people with albinism came when she

What is albinism?

The word “albinism” takes its origin from the Latin word “albus”, which means “white”. Albinism is a genetic metabolic disorder that makes people look very pale. It affects the skin, and also affects the hair and eyes. This often leads to poor eyesight and other problems related to vision. The condition is caused by a shortage of melanin, the body’s natural pigment that influences skin colour and protection against sunlight. People with albinism may produce limited melanin or no melanin at all. (1) Sunscreen and visual aids are essential to help people with albinism to lead the healthiest life possible. There is currently no known cure.

Challenges related to lack of knowledge

People with albinism also face discrimination, attacks, and other serious difficulties in Africa. (2) In the past, some sub-Saharan African tribes regarded people with albinism as “evil”. This led to ostracization and expulsion from the tribe. Today, people with this condition still live in fear for their safety because self-proclaimed “faith healers” have declared them sources of good luck. As a result of this superstition, body parts and bones from people with albinism are sought by rich and powerful people in some areas of Africa because they believe possessing these body parts and bones will bring them riches and fortune. These beliefs lead to contact violence, attacks, kidnappings

FEATURED EVENTS



In addition to the presence in more general media, in June, on the occasion of the celebration of the **International Day of Awareness about Albinism**, our collaborator Allie Magin represented Beyond Suncare at the **National Organization for Albinism and Hypopigmentation (Noah)** event held in Orlando (USA).

In this event for several days, people with albinism and their families shared their experiences and personal stories of empowerment, but two renowned researchers also participated and shared the latest scientific and medical information on the identification and understanding of albinism.

JORNADA POR EL DÍA DE LA MUJER
MUJERES QUE MUEVEN EL MUNDO
Exposición fotográfica "La Fuerza de la Mujer Malgache"

Lugar:
C. Recoletos, 6, 18004 Granada
8 de marzo
Hora: 17h

CUENTACUENTO A CARGO DE YOLANDA AGUADO 'TOWANDA'

Ponencias de:

- Cristina Fuentes: "Mujeres porteadoras en la frontera sur europea"
- Mafalda Soto, Beyond Suncare, "Mujeres Albinas en Africa"
- Sara Antler, de FarmaMundi, "SALUDFEM, Proyecto participativo con mujeres rurales de Baza, Huescar y Guadix"
- Salud García, ONG Agua de Coco, "Empoderamiento de la mujer malgache"

ORGANIZA
Fundación **COVIRAN** **AGUA DECOCO**

CON LA PARTICIPACIÓN DE
BEYOND SUNCARE **FARMA MUNDI**

On the occasion of the celebration of 'International Women's Day', on March 8 we participated in Granada in the **'Women who move the world'** conference, presenting our work with a specific focus on making visible the reality and challenges of women with albinism in Africa.

The NGOs Agua de Coco and Farmamundi also participated in this event organized by the Coviran Foundation.

On November 24, more than a hundred pharmacists participated in **DERMODAY-2022** in the city of Granada. The opening ceremony was attended by Mr. Francisco Cobo, Vice President of the Official College of Pharmacists of Granada, Mr. Tomás Muret, National Member of Dermopharmacy and Ms. Virginia Ortega, member of Dermopharmacy of the Official College of Pharmacists of Granada and organizer. of this day.

The different presentations covered new topics such as CBD cosmetics, food supplements in skin care, trends in the treatment of sensitive skin, intimate care for women, action protocols in dermatopharmacy or myths in cosmetics.

Finally, Mafalda Soto informed the attendees about the work we do at Beyond Suncare. To collaborate with our work, the Official College of Pharmacists of Granada donated a percentage of the tuition fees to this NGO. For them it is all our gratitude.



CLEAR ACCOUNTS

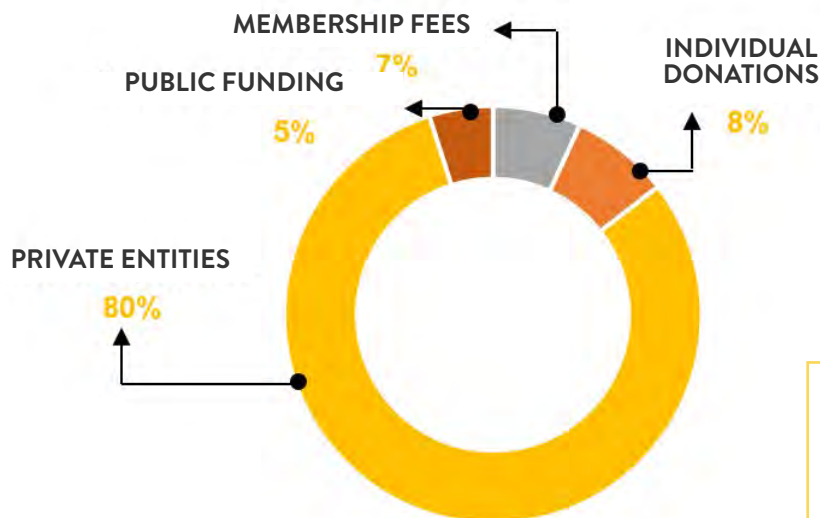
Since 2020 we have edited our accounts and submitted our actions to a transparency report issued by an external entity competent to do so. Likewise, we have made public our Code of Conduct and Internal Regulations. All this information is available on our website.



INCOME

At the end of 2022, the amount of income in the NGO totals €172,533.88. This represents an increase of 13% compared to 2021. Donations from private entities and Foundations, which also include the awards received in 2022, account for 80.57% of total income. The line of income from private donations represents 7.65% of the total, while 6.86% comes from membership fees.

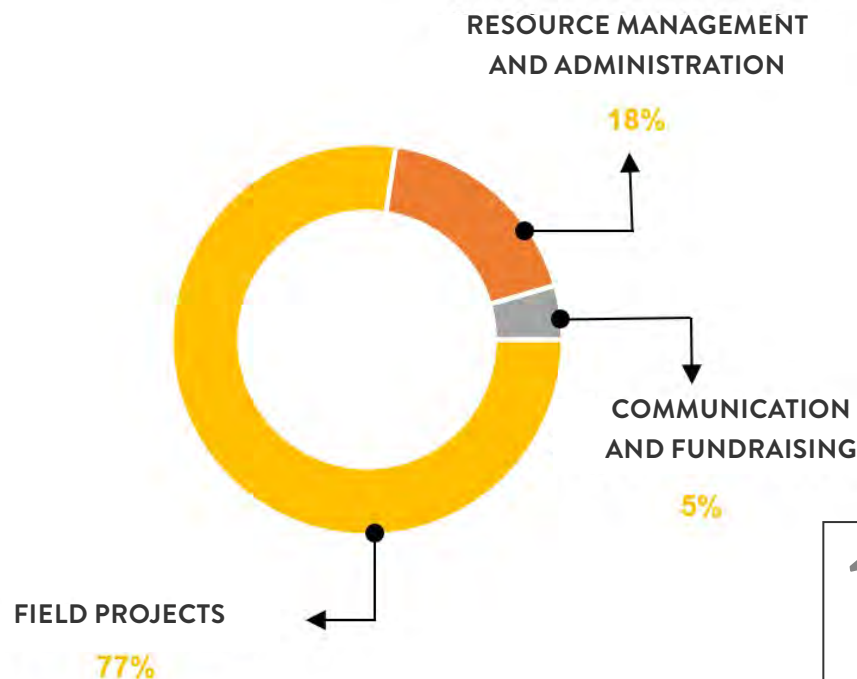
In 2022 we obtained our public subsidy from the Caesars City Council (Málaga), which represented 4.93% of the total fundraising for the year.



172,533.88€
TOTAL REVENUE

EXPENSES

The association's expenses rose significantly in 2022 due to our great dynamism on the ground with the start of projects in two new countries, as well as the consolidation and expansion of our work in Malawi. Specifically, these amounted to €193,442.10, which represents an increase of 28% compared to 2021. Funds directly allocated to projects on the ground amounted to €149,660.17 compared to €116,665.3 in 2021. Resource management and administration expenses account for 18.18% of the total and 4.45% has been used for communication tasks and attracting members and donations.



193,442.10€
TOTAL EXPENSES



MALAWI HUMAN RIGHTS COMMISSION

11

AWARDS AND RECOGNITION

2022 was distinguished by the consolidation of recognitions in the pediatric field with obtaining the Award for international cooperation projects for developing countries from the **Pediatrics and Health Foundation of the AEPap** and the **Subsidy for International Development Cooperation Projects in the Health field of the Spanish Pediatric Foundation**. We are also excited to receive our first public subsidy from the **Casares City Council** through the **Casares Solidario Blas de Infante Award**. Finally, Beyond received the **ALBA (Spanish Albinism Association) Solidarity Fund Award** for the second time.

2022

- **Pediatrics and Health Foundation**
- **Spanish Pediatric Foundation**
- **Casares Solidario Award**
- **ALBA solidarity fund**

2021

- **Gipuzkoa College of Physicians Award**
- **Award from the General Council of Pharmacists**
- **Dermlink International Foundation Award for Dermatology**

2020

- **ALBA Solidarity Fund Award for the Best Solidarity Project related to Albinism**
- **Alicante Medical College Award**
- **Dermlink International Foundation Award for Dermatology**

2019

- **Official College of Physicians of Ourense Award**
- **Dermlink International Foundation Award for Dermatology**

2018

- **ALBA Solidarity Fund Award for the Best Solidarity Project related to Albinism**

2016

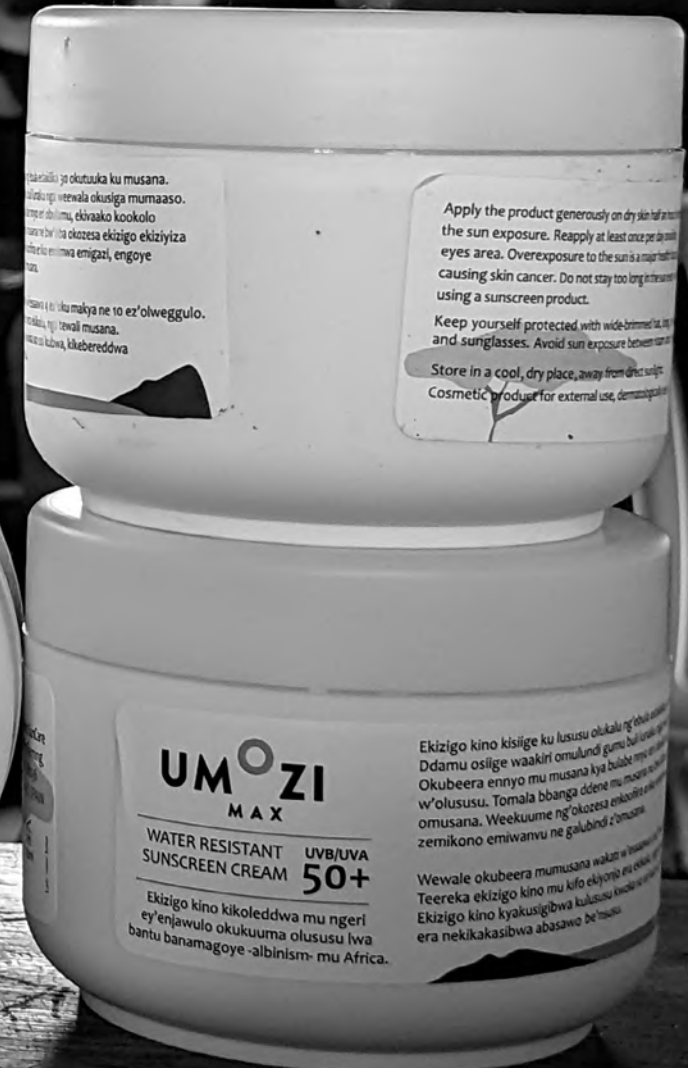
- **Gamechanger 2016 program Emprende in Health Award by Unltd and Laboratorios Lilly**
- **Project chosen Best Practice by the United Nations**
- **American Academy of Dermatology Award**



The Spanish Agency for International Cooperation (AECID) recognizes as Non-Governmental Development Organizations (NGDOs) the "private law entities, legally constituted in Spain, non-profit, that enjoy full legal capacity and to act, that have among their purposes or as an express object, according to their own Statutes, the carrying out of activities related to the principles and objectives of international cooperation for development and that have a structure capable of sufficiently guaranteeing the fulfillment of their objectives

OUR IMPACT IN 2022

12



Despite the large footprint of the war in Ukraine and the consequences of the pandemic continuing to be manifest, 2022 was once again a year of **consolidation and expansion for Beyond**, with a notable increase in funds allocated to

the projects on the ground and their consequent translation into the expansion of their reach and an increase in their social impact.

In Malawi, with a change of direction, the strategic line of institutional strengthening was reinforced with the signing of a Memorandum of Understanding with the Ministry of Health, and the approval of an ambitious project in the south of the country in coalition with two other NGOs and the support of the **Delegation of the European Union in the country**.

In Rwanda we reinforced a project that expanded to new districts and started the implementation of new programs in Uganda and the Democratic Republic of the Congo.

Within our borders we continue to strengthen the governance, betting on the professionalization of our work. In 2022 we publish the [1st Strategic Plan 2023-2027](#) and our [Equality Plan](#) and [Covid Plan](#).

We have been financed thanks to voluntary contributions from partners, collaborators, public subsidies, companies and various national and international recognitions.

To our allies, to all of you who have accompanied us and have believed that the lives of the most vulnerable in the most vulnerable environments deserve to be saved, **ENDLESS THANKS.**



3.653 Beneficiaries with albinism



254 Specialized clinics provided



4 Countries in which we have a consolidated presence



+10,500 UMOZI MAX customized sunscreens distributed



280 Healthcare professionals trained



3.500 People impacted by community awareness actions



5 New agreements with local counterparts



4 Awards and recognitions



56% of people attended are MINORS



254 Educational and awareness workshops aimed at PWA and caregivers

THANK YOU

— REPORT 2022 —



www.beyondsuncare.org