

# ANNUAL REPORT

YEAR 2019



**BEYOND**  
SUNCARE

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“ *Penye nia, pana njia*  
Where there is a wish, there is a will

”

## 1. LETTER FROM THE PRESIDENT

*After more than 10 years of intense work in Africa to improve the quality of life of people with albinism, we are deeply proud and happy to see how our dream of creating an organization that would give continuity to our work in the field over so many years has become a reality.*

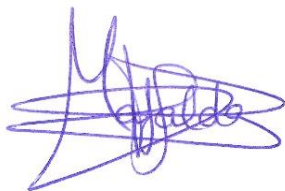
*In our second year of work, we have managed to expand our services to new regions, and maximize the social impact of our actions while starting to work on the creation of alliances that have allowed us to open up opportunities to expand new horizons in the years to come.*

*These have been months of hard work and dedication. We thank each and every one of the people and organizations that have believed in us and our mission for joining us in such an altruistic way.*

*Our story is one of nonconformity, hard work and perseverance. It is the story of the thousands of people we have helped to save, and the thousands of lives we are trying to improve. Our journey has been made in the footsteps of many people with albinism in Africa and those of all those who have joined and continue to join our cause.*

*Together, we have made our dream a new reality every day.*

*Thank you from the bottom of our hearts for making this possible,*

A handwritten signature in blue ink, appearing to read 'Mafalda Soto Valdés', with stylized, overlapping loops and a horizontal line crossing through the middle.

*Mafalda Soto Valdés*

*Chair of Beyond Suncare*



## 2. ABOUT BEYOND SUNCARE

Skin cancer is known as the silent killer, as the initial symptoms often go unnoticed, leading to a late diagnosis and a worsening of the prognosis; especially among people with albinism from African backgrounds.

Poverty and general lack of awareness prevent access to health services, which are generally inadequate and scarce, for people with albinism. With less than 1 dermatologist per 3.5 million people and poor diagnostic and treatment facilities, many sub-Saharan countries do not have sufficient capacity to adequately treat skin diseases. This, combined with the lack of prioritization of national health systems in the field of dermatology and specifically of albinism, has led to the current incidence of epidemic skin cancer among Africans with albinism.

For all these reasons, prevention is essential. In Africa, sunscreen saves lives.

Our team's in-depth knowledge of the skin and reality of the beneficiaries, combined with the experience of the world's leading chemical company BASF, gave life to the first sunscreen specially designed for the prevention of skin cancer in people with albinism in Africa. The result is a sunscreen with SPF 50+, high water resistance, with a broad spectrum (protects against UVA and UVB radiation) and with a unsophisticated manufacturing process since the objective is local production in African countries.

BEYOND SUNCARE guarantees access to this unique, high quality specific protection through local production and free distribution. Distributions are accompanied by education and awareness campaigns and involve people with albinism themselves. We work with local albinism associations promoting social inclusion and making political advocacy that contributes to structural and long-lasting changes.

## 3. VISION, MISSION, VALUES

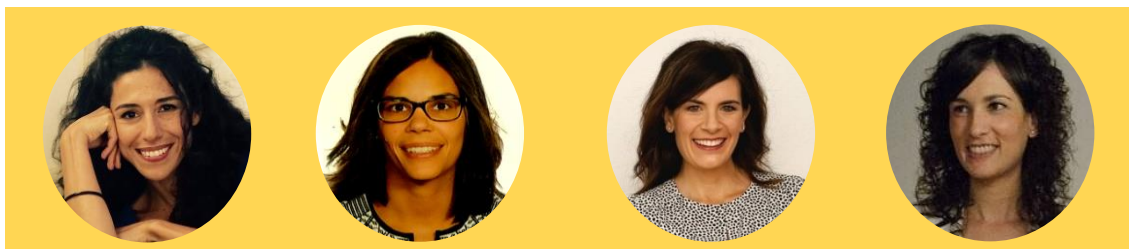
- OUR VISION: We fight for a world where the human rights of all people with albinism are respected, where they enjoy equal opportunities and live a free life without fear, fending for themselves and being who they really are.
- OUR MISSION: We go beyond sun protection to ensure that no person with albinism dies needlessly from skin cancer. We promote their integration into society by encouraging more

tolerant societies and providing them with dignified care that will help raise their self-esteem and self-confidence.

■ OUR **VALUES**: Unity, innovation, commitment, authenticity, reliability.

## 4. MANAGEMENT AND **ADVISORY BOARD**

### 1. MANAGEMENT TEAM:



**Mafalda Soto**

*President*

**Ruth Francisco**

*Vice President*

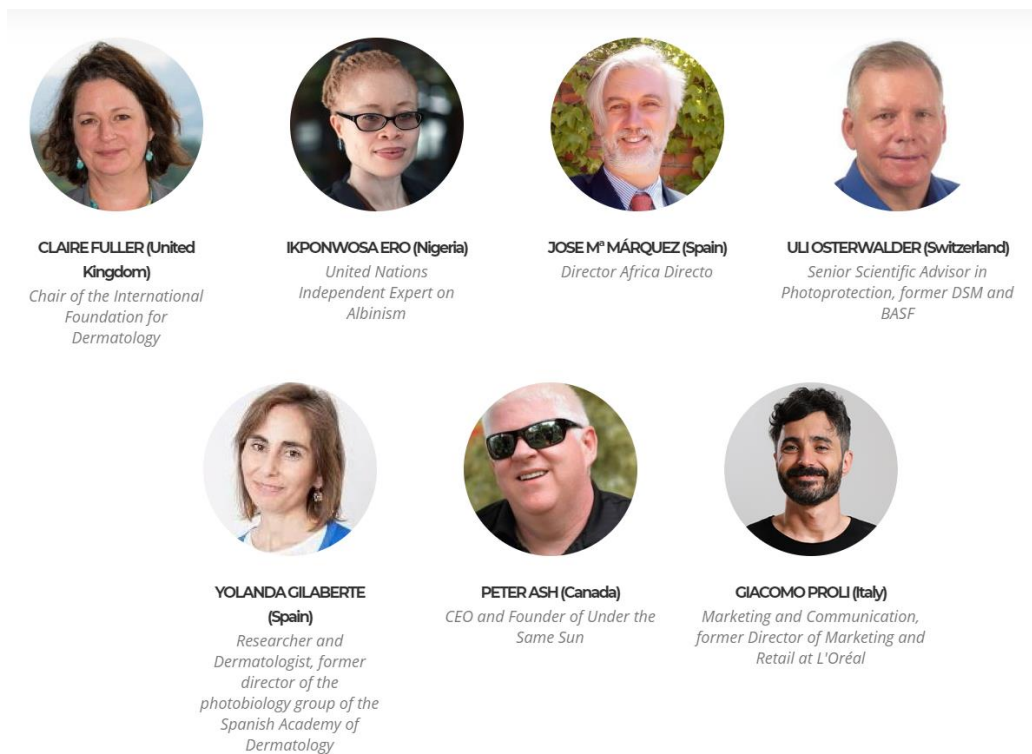
**Lorea Bagazgoitia**

*Secretary*

**Beatriz Montero**

*Treasure*

### 2. ADVISORY BOARD:



**CLAIRE FULLER (United Kingdom)**

*Chair of the International Foundation for Dermatology*

**IKPONWOSA ERO (Nigeria)**

*United Nations Independent Expert on Albinism*

**JOSE Mª MÁRQUEZ (Spain)**

*Director Africa Directo*

**ULI OSTERWALDER (Switzerland)**

*Senior Scientific Advisor in Photoprotection, former DSM and BASF*



**YOLANDA GILABERTE (Spain)**

*Researcher and Dermatologist, former director of the photobiology group of the Spanish Academy of Dermatology*



**PETER ASH (Canada)**

*CEO and Founder of Under the Same Sun*

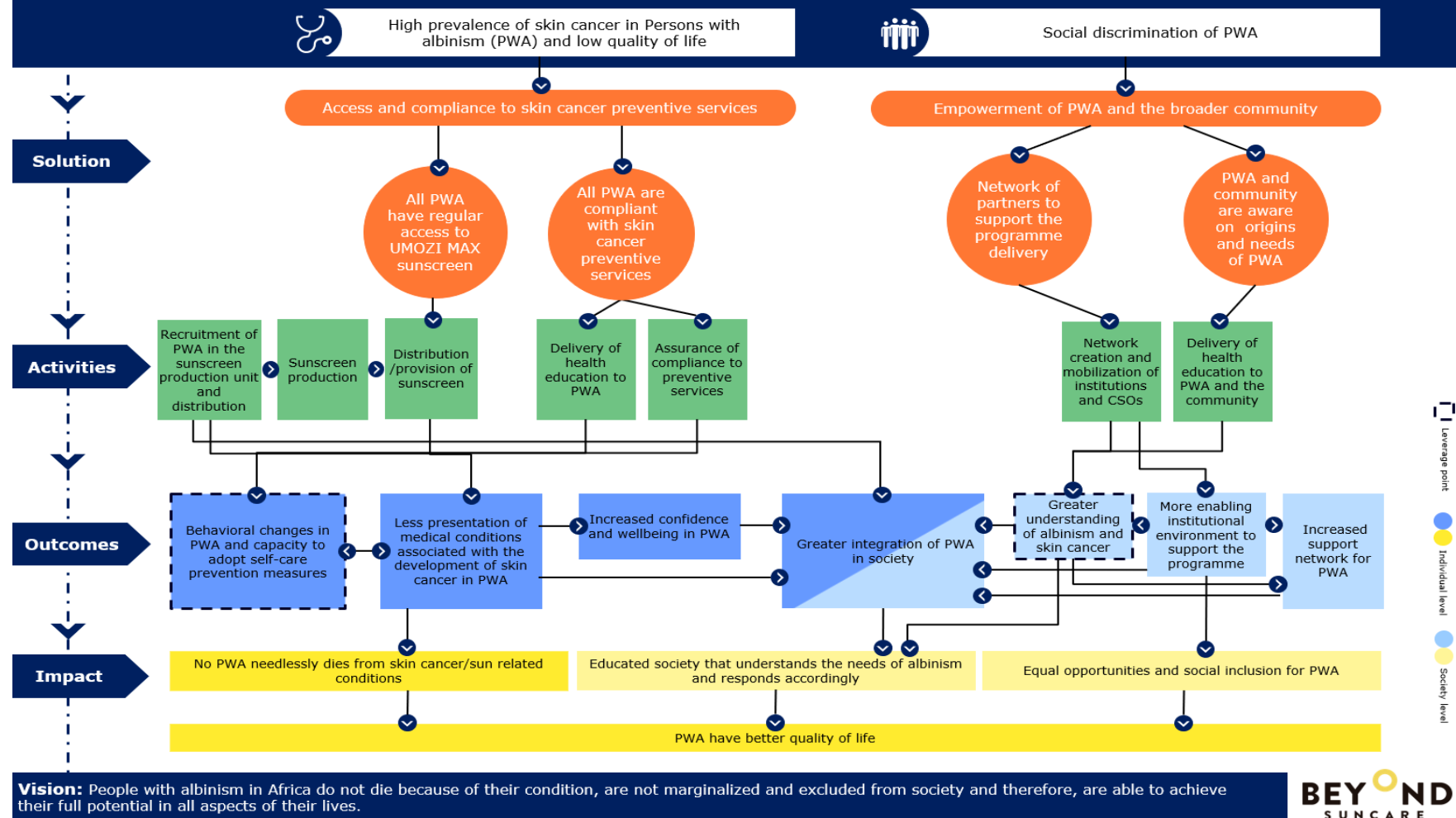


**GIACOMO PROLI (Italy)**

*Marketing and Communication, former Director of Marketing and Retail at L'Oréal*

## 5. THEORY OF CHANGE

**Problem:** In Africa, people with albinism - a genetic condition that disrupts the body's production of melanin, reducing pigmentation in the skin, eyes and hair- are regularly stigmatized because of their pale appearance. Some are even targeted for their body parts, used in witchcraft charms thought to bring wealth and fortune. Marginalization and lack of general awareness impedes people with albinisms' access to health services, education, housing and employment; restricts the delivery of preventative health education; and isolates them from their communities and families. This has produced a skin cancer epidemic among Africans with albinism.



## 5. DESCRIPTION OF OUR WORK



*In Sub-Saharan Africa live more than 200.000 Persons with Albinism without sun care education and access to adequate sun protection*

**BEYOND SUNCARE** improves their quality of life ensuring that they have access to high quality sun-protection through the local production and free distribution of a sunscreen specially designed for their needs. Distributions are accompanied by education and awareness campaigns

**BEYOND  
SUNCARE**

f beyondsuncare

beyondsuncare.org

### THE PROBLEM

Albinism is poorly understood in many African societies. Dehumanizing myths and superstitions surround the condition, with misconceptions leading to abandonment and violence. Persons with Albinism (PWA) are unlikely to get educated due to stigma, fear and lack of safety mechanism in schools, and they usually earn their living with menial outdoor jobs.

The health consequences of the combination of high ambient UVR and prolonged outdoor periods are severe among PWA. The risk of developing skin cancer in PWA is up to 1000-fold higher than in the rest of African population. In Tanzania, where stigma is "rife" only 1 out of 10 PWA live beyond the age of 30.

Sunscreen provision is alarmingly poor across Africa, most health facilities do not have sunscreens, nor offer advice on sun protection to PWA, nor is albinism included in health programs.

### THE SOLUTION

**Beyond Suncare** is a leading organization in the provision of sun-protection for PWA in Sub-Saharan Africa.

With the support of leading chemical company BASF, Beyond is behind the development of the first sunscreen specially designed for the prevention of skin cancer in PWA. Produced in local production units, the cream is distributed to the most remote areas through mobile clinics, health centres, schools, etc.

Beyond Suncare ensures the provision of education and awareness to users and their families, promoting their insertion into society through dignified care that helps to raise their self-esteem and self-sufficiency.

We do advocacy and in addition to local health professionals, we work with associations of people with albinism in the distribution and provision of education.



### ADDED VALUE

- ✓ Formula specifically tailored for the skin, reality and needs of PWA of Sub-Saharan Africa
- ✓ Through the provision of education it helps to clear misconceptions surrounding albinism
  - ✓ Follows up adherence to the treatment addressing compliance challenges
  - ✓ Works on understanding the needs and preferences of the users
- ✓ Recycles the packaging: assessing compliance, reducing costs and minimizing the environmental impact

### SOCIAL IMPACT IN 2019

4,000 PWA received Beyond Suncare services in Tanzania, Malawi and Rwanda, 50% are children

70% decrease in sunburn among new registered beneficiaries

97% of the beneficiaries recommend Beyond services and declares a positive impact in their self-confidence

30% of the local staff working in the sunscreen production in Tanzania has albinism



### GOALS AND EXPANSION STRATEGY FOR 2019-2022

#### BEYOND SUNCARE IN 2019

- Launching of UMOZI MAX, a new formula with greater cosmetic elegance and effectiveness.
- Study on the acceptance and adherence of the new formula and photoprotection services in Malawi
- Pilot programs in Senegal & Rwanda
- Beyond Suncare hands over programme management in Tanzania

#### BEYOND SUNCARE IN 2020

- Launching Beyond Suncare programme in 7 districts of Malawi with the local Albinism Association of Persons with Albinism in Malawi (APAM) and the Ministry of Health
- Identification for pilot launch in Uganda
- Pilot of the programme in Mozambique
- 5,000 direct beneficiaries

#### BEYOND SUNCARE IN 2021-2022

- Construction of a sunscreen production unit and launch of nationwide sun protection package in Malawi
- Pilot of the programme in Uganda
- Identification for pilot launch in DRC
- 9,000 direct beneficiaries receive the services

## 6. ACTIVITIES IN 2019

### I. HANDOVER OF PROGRAMME MANAGEMENT TO KILIMANJARO CHRISTIAN MEDICAL CENTRE (KCMC) IN TANZANIA

In 2019 Beyond Suncare handed over the management of the Kilimanjaro Sunscreen Production Unit (KSPU) to the Regional Dermatology Training Center at the Kilimanjaro Christian Medical Centre (KCMC) in Moshi, Tanzania. This transfer of responsibility includes the management of raw materials, personnel and distribution of products manufactured in the unit. In this way, it already operates autonomously and sustainably, with occasional support from well-wishers and collaborators. Beyond Suncare remains a key partner with support in the form of technical assistance and know-how.

Beyond Suncare assists the Regional Dermatology Training Centre (RDTC at KCMC) with technical support and all necessary documentation for the registration of the new formula with the Tanzanian Foods and Drugs Authority. The protocol for the acceptance comparison study of the new formula with the previous one was developed by Beyond Suncare for the RDTC at KCMC, following a similar format to the one we carried out in Malawi.



We also facilitated RDTC's relationship with BASF, the main chemical laboratory with which we work and which provides us with technical assistance and raw materials, so that they continue to support RDTC with raw materials.



## II. COMPLETION OF THE DEVELOPMENT OF A NEW SUNSCREEN FORMULATION WITH MORE EFFICACY AND COSMETIC ELEGANCE

In 2019 we have completed three years of case work on developing and improving a new formulation for our sunscreen.

The **"UMOZI MAX"** sunscreen that Beyond Suncare has developed for people with albinism in Sub-Saharan Africa with thanks to the support of the chemical company BASF, takes into account their sensory preferences. For three years, the beneficiaries tried out various formulations and discarded the ones they liked the least to focus on those they found most enjoyable to apply.

We labeled the packaging in the local languages so that they could understand what was being applied, specifically in Portuguese, French, Kinyarwanda, English, Swahili and Chichewa.

"UMOZI", comes from the Chichewa word (official language of Malawi) UMODZI which means union and its formula is a great improvement over the previous Kilisun formula.

Unlike the trend in the West, East Africa loves intense perfumes so in our formula we opt for a soft floral perfume with low photosensitizing action.

In addition, UMOZI MAX has SPF 50+, high water resistance and broad spectrum (UVA and UVB coverage). Its formulation includes very safe ingredients, minimizing undesirable effects. We have chosen sunscreen filters with large molecule size to prevent penetration into the deeper layers of the skin. UMOZI MAX does not include controversial sun protection filters in its formulation, the other ingredients in its composition have not reported photosensitizing properties or effects on the endocrine system.

**The preservative used in the formulation is of natural origin and environmentally friendly.**

The packaging is recycled along the same lines. In our model, as in Tanzania, people with albinism have to take the empty containers to the clinics to be given new ones. This is done with a triple objective: at the same time as promoting environmental care, compliance with treatment is evaluated and, finally, responsibility and self-care measures are encouraged among users.

The formula of our sunscreen combines high efficacy and safety, it has been adapted to the users' taste and has been adapted to be manufactured in unsophisticated facilities, giving work to the people with albinism themselves.

In December we redesigned the branding of UMOZI MAX with an image more in line with the identity of Beyond and inspired by Lake Malawi, where we have started to distribute it. The colors are reminiscent of earth, clay, wood and sun; elements of everyday life in Africa.



### III. STUDY OF THE ACCEPTANCE AND EFFICACY OF A SUN PROTECTION PACKAGE BESPOKE FOR PERSONS WITH ALBINISM LIVING IN MALAWI

It is estimated that around 8,000 people with albinism (PWA) live in Malawi. As is the case in neighboring Tanzania, in Malawi, skin cancer is the leading cause of death among PWA with advanced skin cancers in the third or fourth decade of life. Efforts to address this epidemic have been valuable in Malawi, where the Government, in line with the Regional Action African Plan on Albinism (2017-2021) and the National Action Plan on Albinism, has included sunscreens in the list of essential medicines and allocated budget for the procurement of sunscreens.

However, despite the efforts, many problems limit the effectiveness of the measures implemented. There is a lack of knowledge about albinism, as many health institutions do not provide advice on photoprotection, nor is albinism included in health education programmes. With almost 19 million inhabitants, Malawi has three dermatologists and two centres with cancer therapy.

In 2017, Beyond Suncare, in collaboration with the Association of People with Albinism (APAM) and with the support of the United Nations and the Ministry of Health, carried out a country assessment exercise on access to sun protection services for PWA.

The assessment mission highlighted the need to decentralize sun protection services to reach all people with albinism, most of whom live in rural areas, as well as the urgency of improving the efficacy and safety of available sunscreens and increasing awareness of sunscreen and its use: 80% of the PWA interviewed used the creams incorrectly (e.g. evening hours and under clothes) and in most cases the creams did not reach rural health facilities, causing hundreds of units to expire in central and district hospital warehouses. In addition, a study was carried out to compare the performance of commonly used sunscreens on a local level and UMOZI MAX, with much better efficacy and safety results for UMOZI MAX.

These factors prompted the development of a preventive programme focusing on capacity-building, education, improved formulation of sunscreens and decentralization of services. In February 2019, after approval by the Malawi National Social Science and Humanities Research Committee, the dermatology department of Kamuzu Central Hospital, in collaboration with other researchers, launched the research study: *"Evaluation of the acceptance and efficacy of a sun protection package bespoke for Persons with Oculocutaneous Albinism living in Malawi"*, with the aim of testing and evaluating the effectiveness and acceptance of the ["Beyond Protection Package"](#).



This package included the provision of UMOZI MAX along with a photo-education program. The study showed a decrease of up to 45% in sun-related skin lesions (skin cancer precursors), a >95% preference for UMOZI MAX over other previously used sunscreens, and satisfaction levels with the complete program of more than 95%.



The [final report](#) is published on the official website of [“ACTION ON ALBINISM”](#), will be presented in the coming “5<sup>th</sup> European Days of Albinism” and is being adapted for publication in the Journal of the European Academy of Dermatology and Venereology.



Now that the effectiveness and acceptance of the sun protection package has been confirmed and evidenced, Beyond Suncare, in partnership with the Ministry of Health and APAM, will launch a pilot programme in 2020 to expand services to 4 districts in Malawi: Mzimba North, Mzimba South, Ntechu and Dedza while working on the formalization of a PPP for the establishment of a local production unit of **UMOZI MAX**, following the model initiated by Beyond Suncare in Tanzania and aiming to meet the needs of the whole country.





#### IV. LAUNCHING OF PILOT PROGRAMMES IN SENEGAL AND RWANDA

In 2019 we launched two pilot programmes in Senegal and Rwanda and we are working on a third in Mozambique for the first half of 2020.

Our way of working is through partnerships with international organizations or recognized CSOs that work directly on the ground with groups of people with albinism. Beyond Suncare and the local partners identify the staff that is trained by us in the [provision of the services](#) following the standards, working methodology and data collection of Beyond.

In the case of Rwanda, we work directly with the local association Health Alert Volunteers, composed of local doctors who organize mobile ophthalmology and dermatology clinics regularly in Kigali and in the Western Province. In Senegal we work in the Thiés region with the NGO ASMUN-volunteers around the world and with ANAS (Association Nationale de l'Albinisme au Sénégal).



After preparing all the educational and training materials and packaging the creams in the local languages (French, Wolof and Kinyarwanda), we proceed to send sending all the materials and training those responsible in the field, providing the program for monitoring adherence and measuring impact translated into the local language ([Epi Info](#)), and sending all the materials. The clinics and distributions began in the last half of 2019, so we will receive the first reports in the first quarter of 2020.

## V. ACTIVITIES CARRIED OUT IN SPAIN

### Launch of new branding and website:

Last year 2019 we formalized the change of name of the organization from **Kilisun Care** to **Beyond Suncare** (officially registered in October 2019) and developed new branding. In April we launched the [website](#) after months of intense work with professionals and volunteers from various disciplines such as photographers, media, IT specialists and translators to whom we are deeply grateful for their work and collaboration. The site is trilingual in **English, French and Spanish** and has direct access to the organization's RRSS and blog which we try to update monthly.

We also launched accounts on **YouTube, Instagram and Facebook**. In December we incorporated a communications manager to the team and implemented a communication plan that allows us to communicate our actions in a more efficient and professional way. At Christmas we started our first **membership recruitment campaign**.

### Dissemination and recognition activities:

In 2019 in Spain we did outreach activities and participated in various forums and events such as the **Spanish National Congress of Medical Cooperation** or [#TEDxXardindoPosío](#). We have also shared our history and our work in various media ("[I think, then I act](#)", etc.) Several regional and national newspapers have made our work visible and spread it, such as "[El País](#)", La Voz de Galicia or El Faro de Vigo.

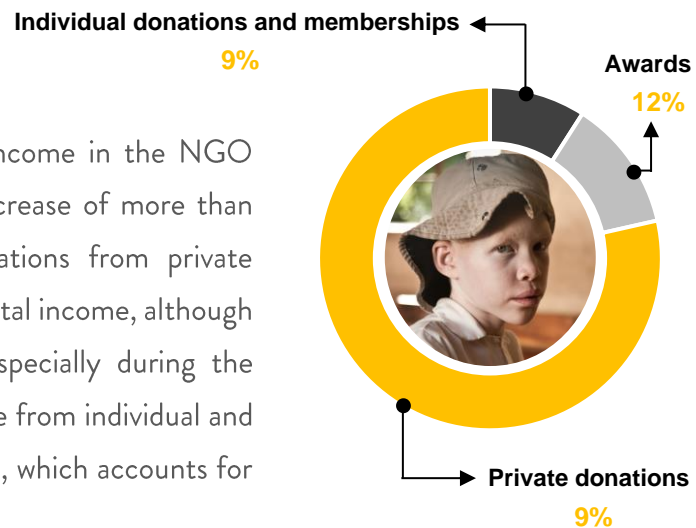
2019 was also a year of awards and recognition in which through the Spanish Academy of Dermatology we obtained the **Dermlink Award** from the **International Foundation for Dermatology** and the first prize from the Central Section of the Spanish Academy of Dermatology.

Likewise, the co-founder and president of Beyond Suncare, Mafalda Soto was included in the sixth position in the ranking of the [Economic Leaders of Tomorrow](#) elaborated by the Choiseul Institute and in which the trajectory and leadership capacities as well as the human capital potential of leaders from diverse disciplines under 42 years of age are recognized.

## 7. FUND ADMINISTRATION

### INCOMES

Throughout 2019, the amount of income in the NGO totals 49,558.46. This means an increase of more than 125% with respect to 2018. Donations from private entities account for 78.54% of the total income, although in the last quarter of 2019 and especially during the Christmas campaign, a line of income from individual and member donations has been initiated, which accounts for 9.06% of the total.

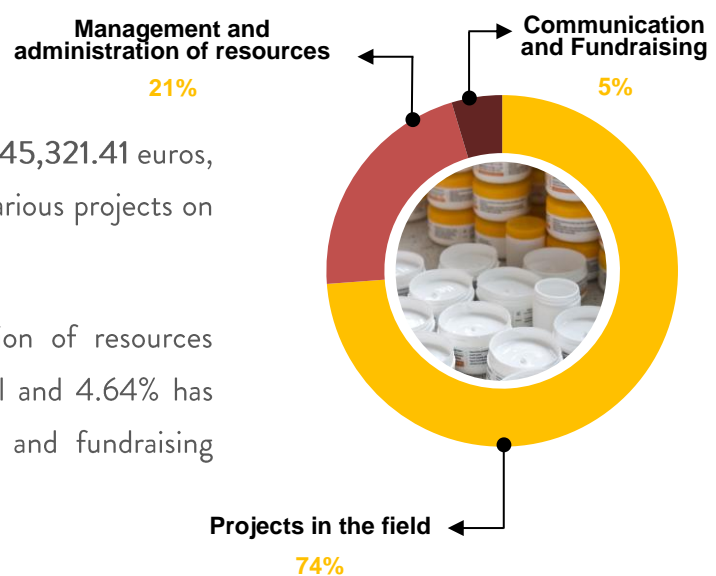


Likewise, during 2019 another source of income comes from prizes awarded to the NGO, which represent 12.4% of the total.

### EXPENDITURES

In 2019, the NGO spent a total of 45,321.41 euros, of which almost 74% went to the various projects on the ground, mainly in Malawi.

The management and administration of resources costs represents 21.5% of the total and 4.64% has been allocated to communication and fundraising activities.



## 8. ACKNOWLEDGEMENTS



Volunteers, collaborating entities that support us with their services and financially, partners and donors, prizes obtained. To all of you:

THANK YOU FOR MAKING IT POSSIBLE!





## ¿WHAT CAN YOU DO?

Thanks to people like you, we have managed to improve thousands of lives in Africa and restore dignity and hope to one of the most forgotten groups in the world.

Would you like to join us?

- **Donate** and make our work possible where it is most needed
- **Become a member** with a minimum monthly fee of 8 euros and help us to go further
- **Collaborate as a company** in many different ways
- **Help us get more members** through your contacts, or by organizing sports, social or cultural events.
- **Volunteer and contribute your time and knowledge**

If you want to know more, do not hesitate to contact us and/or follow us on social networks:



**THANK YOU**

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