

# 2022 **ACTIVITY REPORT**



**ORDER OF MALTA**  
LEPROSY RELIEF

**CIOMAL FOUNDATION**

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# I

# A WORD FROM THE CHAIRMAN

In 2022, CIOMAL's activities in Cambodia continued smoothly, including screening for the disease and socio-economic rehabilitation, making up almost entirely for the delay caused by the pandemic. In Brazil, our actions have also seen sustained development, not only in telemedicine but also in offering a world first to people affected by leprosy: the manufacture of orthopedic shoes using 3D printers. Thanks to the Sovereign Order of Malta's diplomatic network, we were also able to provide aid in Mauritania, where people disabled by leprosy were assisted by CIOMAL on Islamic soil.

At the same time, our teams in Geneva continued their relentless work to raise awareness of the continuing ravages of leprosy. After a magnificent concert given in the spring by the musicians of the *Orchestre des Nations*, we once again drew the attention of the international community at the UN Human Rights Council to encourage access to healthcare for people affected by leprosy. On the medical front, we took part in several international leprosy congresses, such as the European Dermatology Congress in Milan, the International Leprosy Congress in Hyderabad (India) and the Brazilian Leprology Congress in Vitoria (Brazil). Finally, we brought together our largest donors for the first "Cercle des Bienfaiteurs" dinner.

At head office, Ms. Lauren Bouvier, who worked with great dedication for CIOMAL for the last four years, left the foundation last autumn to take on new responsibilities. Ms. Olivia de Villaine took over from her in November, bringing her intelligence and energy to our worthy cause. We thank them both from the bottom of our hearts for their commitment.

It is important to note that leprosy continues to infect nearly 200,000 additional persons every year. The loyal and generous support of all people of goodwill towards CIOMAL is therefore infinitely valuable, as it contributes to our vision of a world without leprosy and enables us to continue our work tirelessly, with tenacity, courage and dedication. The CIOMAL teams have been providing impeccable quality care for 65 years, in the spirit of the Order of Malta, seeking the face of Jesus Christ in the hearts of those who turn to us.

The material generosity of our private and institutional donors is considered a blessing by the beneficiaries that our valiant teams have been able to help. We therefore encourage you to dream with us of a world without leprosy, to join us and to support us:

<https://touscontrelalepre.ciomal.org/> !

Thierry  
Zen Ruffinen  
Chairman







## OBJECTIVES OF THE CIOMAL FOUNDATION

CIOMAL is a Swiss foundation based in Geneva and recognized as being of public utility. It has special consultative status with the UN Economic and Social Council since 2018. Its main objective is to fight leprosy and the ensuing disabilities, as well as all forms of exclusion linked to the disease, throughout the world.

Confronted with leprosy and its medical and socio-economic consequences for centuries, the Order of Malta has never ceased to operate against this stigmatizing disease. To make an appropriate contribution to its eradication, CIOMAL was created in Geneva in 1958. In 1999, it was incorporated as a non-profit foundation under Swiss law and renamed the Order of Malta's CIOMAL Foundation (Campagne Internationale de l'Ordre de Malte contre la Lèpre).

Today, the CIOMAL Foundation develops projects based on two fundamental axes:

- **disease prevention** (prophylaxis and early detection)
- **rehabilitation for those who have recovered**

To achieve its objectives, CIOMAL acts on several levels:

- **medical care and rehabilitation through polychemotherapy**, treatment of the leprosy reaction and the consequences of the disease, as well as therapeutic care;
- **prevention of disability**, through training for healthcare staff and people affected by leprosy;
- **early detection**, through active case-finding campaigns in the most affected regions;
- **socio-economic rehabilitation of cured people** through financial support for micro-enterprises, vocational training, house building or renovation, study grants and food aid;
- **awareness campaigns** aimed at stopping contagion and reducing severe handicaps as well as the stigmatization of people affected by leprosy and their families.

On 31 December 2022, the Foundation Board was constituted by:

<b>Chairman :</b>	Mr Thierry Zen Ruffinen
<b>Chief Financial Officer :</b>	Count Manfredo Radicati di Primeglio
<b>Members :</b>	Prof. Philippe Jaeger
	Dr. Laila de Laguiche
	Mrs Hélène Genillard
	Mr Raymond Loretan
	Mrs Verena Vorwerk
	Mr Charles-Louis Notter
	Mr Hervé Arot
<b>Executive Committee :</b>	Mr Thierry Zen Ruffinen
	Count Manfredo Radicati di Primeglio
	Mrs Marie-Axelle Annicchiarico
<b>Head of Operations :</b>	Mrs Carole Vann
<b>Head of Development :</b>	Mrs Olivia de Villaine



From left to right:

Mr Charles-Louis Notter • Mrs Olivia de Villaine • Mrs Verena Vorwerk • Mrs Hélène Genillard • Dr Laila de Laguiche • Mr Thierry Zen Ruffinen •

Mr Hervé Arot • Mr Raymond Loretan • Prof. Philippe Jaeger • Count Manfredo Radicati di Primeglio • Mrs Carole Vann • Mrs Marie-Axelle Annicchiarico



## HANSEN'S DISEASE

Hansen's disease, more commonly known as leprosy, is a chronic infectious disease caused by the bacillus *Mycobacterium leprae* that affects the nervous system, skin and mucous membranes, resulting in severe disability. Contagious, it has an incubation period of between 3 to 30 years, and symptoms can sometimes appear 10 years after infection, making early detection of the disease extremely difficult.

The disease is strongly linked to a country's level of development, and spreads more easily in the most disadvantaged environments affected by poverty, lack of hygiene and malnutrition.

Leprosy affects almost 200,000 additional persons every year, mainly in South-East Asia, Africa and South America. According to the World Health Organization (WHO), 140,000 cases were diagnosed between 2020 and 2021, but these latest figures are difficult to validate due to the absence of censuses for these two years because of the restrictions imposed by the Covid 19 pandemic.

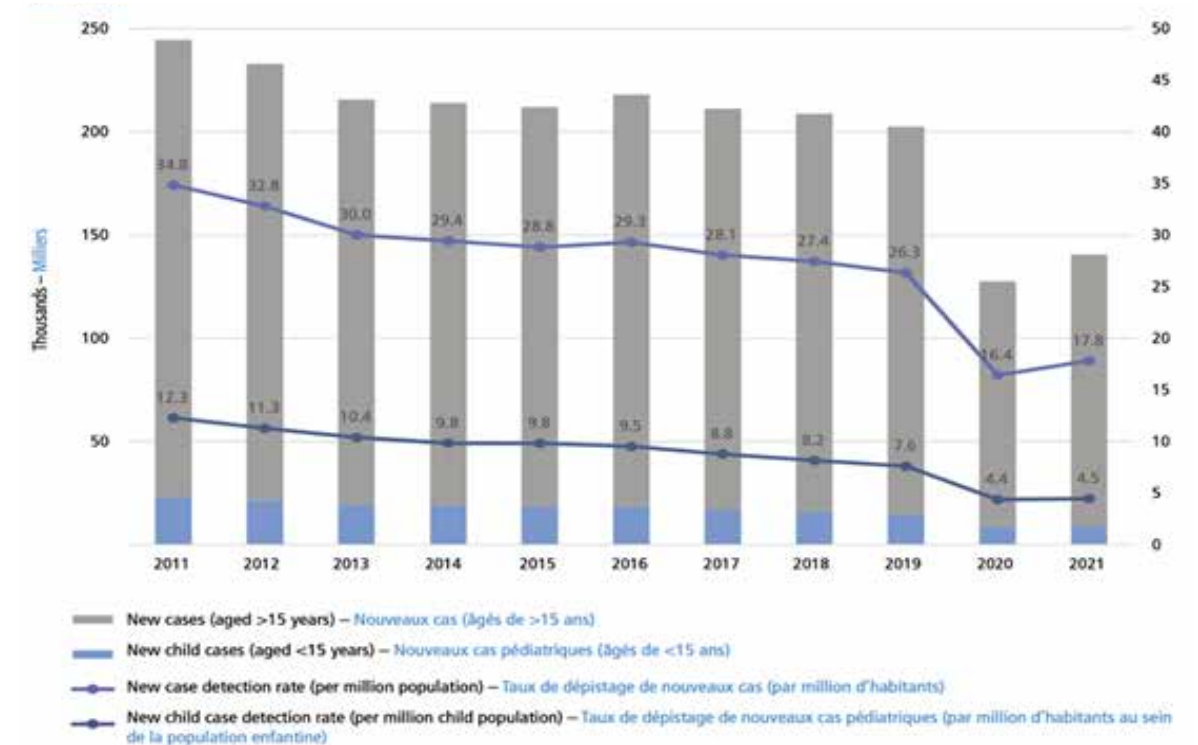


*Cambodge, photo of a beneficiary atteint of the disease*

Lack of treatment can lead to permanent damage to the skin, peripheral nervous system, limbs and eyes, as well as a total loss of feeling in the feet and hands.

### Leprosy in the world over the last 10 years

Trends in number and rate of new leprosy cases detected globally  
(adult cases and children), 2011–2021



Source : OMS

Treatment is provided free of charge by the WHO and involves taking three antibiotics (multi-drug therapy) over a period of 6 to 18 months. However, in many cases, the disease is diagnosed too late, leading to severe disability. Although the damages can be improved by reconstructive surgery, the families find themselves forever scarred, isolated and rejected.

CIOMAL's work remains essential in helping these families achieve lasting autonomy and reintegration into society, as well as in the early detection of leprosy in the worst-affected areas.



## 1. Cambodia

CIOMAL has been present in Cambodia for 30 years, precisely since the first elected government entrusted the Sovereign Order of Malta with the task of creating the National Leprosy Elimination Programme after the ravages perpetrated by the Khmer Rouge.

This programme, in association with the Ministry of Health and the Ministry of Social Affairs, Veterans and Youth Rehabilitation, enables CIOMAL to act at several levels:

### Early detection

During 2022, twelve campaigns were conducted throughout the country, during which CIOMAL teams visited 954 former leprosy patients, 1,634 members of their households and 8,232 people living in their immediate environment.

A total of 44 new cases were detected (30 men, 8 women and 6 children under the age of 15).

The decline in the number of cases recorded can be explained by the following factors:

- the merger of the national contact tracing programme and leprosy post-exposure prophylaxis (LPEP) - in line with WHO recommendations since early 2021 - making screening more time-consuming ;
- the higher level of economic migration out of the country and towards cities, particularly the capital ;
- the effectiveness of community awareness strategies and the distribution of a prophylactic drug (Rifampicin) to contact cases ;
- restrictions linked to the Covid 19 epidemic, making it difficult for teams to visit certain isolated communities.

In general, new cases of leprosy in Cambodia are decreasing thanks to the joint efforts of the Ministry of Health, the WHO and local partners such as CIOMAL.

### Socio-economic rehabilitation

Since 2002, CIOMAL has been pursuing its socio-economic reintegration project, focusing on reintegrating people isolated by leprosy into their communities. This project focuses on various areas leading to the reintegration of sufferers into society :

- The study grants are intended for young people affected by leprosy or those living in a family where a member suffers from leprosy. CIOMAL provides study materials, accommodation and food. The team regularly visits the beneficiaries and follows up with their families and teachers. A total of 52 students (5 university students, 27 secondary school pupils and 20 primary school pupils) have benefited from this support. 15 bicycles have also been distributed to students to make it easier for them to get to classes.

- The "cow-banking" activity initiated following the Covid 19 pandemic has continued successfully. CIOMAL makes cows available to People Affected by Leprosy (PAL); after giving birth to two calves in 2 years, the cow is made available to another family affected by leprosy. The calves then become the property of the beneficiary. In 2022, 38 cows were lent under this initiative.



Construction of a well for a beneficiary family

- Building wells: CIOMAL has provided access to water by building three wells in isolated areas. As a result, people suffering from the disease and with reduced mobility have seen their daily lives improve. Water filters to make the water drinkable have been installed for 37 families.

- Construction of toilets: as hygiene is essential to healing and preventing the disease from spreading, 9 toilets were built.

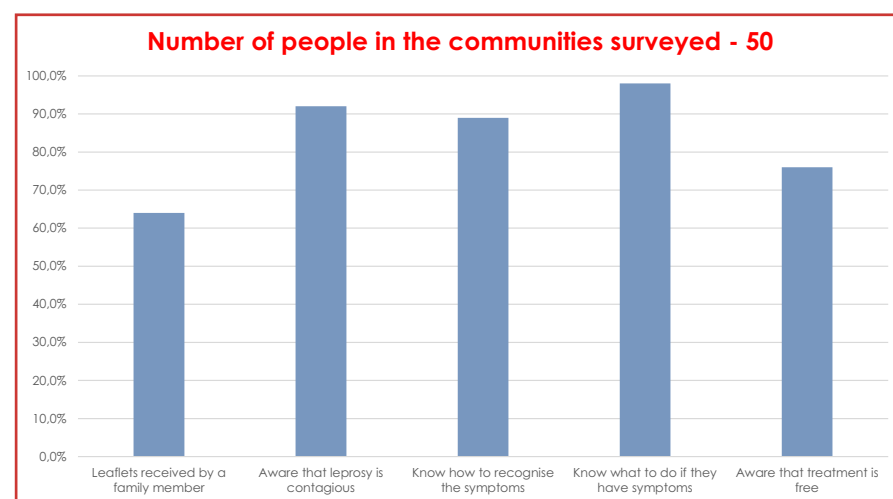
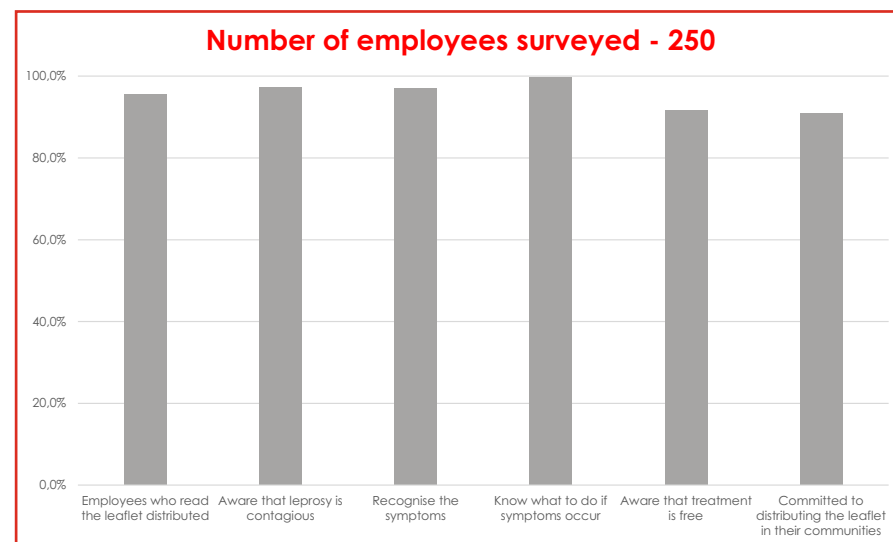
- Emergency situations: CIOMAL provided emergency food aid to 18 of the most destitute leprosy sufferers.

### Awareness campaigns

The aim of raising awareness is to help recognize the early signs and symptoms of leprosy, and to inform people about complications and treatment in order to reduce transmission and the disabilities that can result. Awareness campaigns also help to inform people affected by leprosy about the services of the Kien Khleang Leprosy Rehabilitation Centre (KKLRC) and to increase knowledge of the disease in order to reduce stigmatization in the communities.

In 2022, the CIOMAL team, accompanied by staff from the Ministry of Social Affairs, Veterans and Youth Rehabilitation and the National Leprosy Elimination Programme, carried out awareness-raising activities in 18 garment factories in the provinces of Takeo and Kampong Speu, meeting 41,275 female workers.

CIOMAL also visited 280 families in 85 villages in 18 provinces to conduct awareness-raising activities.



### Capacity building / training

Appropriate treatment of wounds, the use of assistive devices and other preventive techniques can help leprosy patients to manage their impairments and prevent them from worsening.

In 2022, 280 PALs (People Affected by Leprosy) and 428 households were trained in self-care, wound and injury prevention.

At the same time, 88 of the Association's PALs took various training courses on work, networking and organization.

CIOMAL teams were given English lessons as well as communication and website development classes. Training for orthopedic assistants continued in 2022 (13 pairs of orthopaedical shoes, 12 orthopaedical sandals, 26 pairs of shoes for club feet).

In 2022, 834 members of the health services benefited from capacity building in leprosy awareness.

Activity	Impact	Direct and indirect beneficiaries
12 Active search/tracking campaigns	Prevention and early detection	10'820
18 Awareness campaigns	Prevention - Information	41'275
Study grants	Education and training / autonomy	52
Loans for micro-businesses	Financial autonomy	38
Construction of sanitary facilities	Health emergency / hygiene	9
Construction/renovation of houses	Social protection and reintegration	7
Drilling of wells	Access to water / hygiene	3
Distribution of water filters	Access to drinking water	37
Food supplies	Emergencies	18
Self-care training	Autonomy	428
Training for people affected by leprosy	Learning / networking / independence	88
Training for employees	Capacity and skills building	834

**Cost of a well :**  
between 500 and 950 USD depending on the region

**Cost of a house :**  
on average 3,500 USD





Awareness campaigns in textile factories



Active research campaigns in villages

### Other activities

- The 2nd Congress of the Cambodia Association of Hansen People with Disability (CADH) was held on 17 June 2022 in the city of Kampong Cham under the theme of establishing the association's nationwide network. More than 130 participants - 69 people with disabilities from 25 provinces, 41 PALs from Traeung village and 20 partners - attended the event.

- The CADH members took part in various meetings and workshops in preparation for the Asia Pacific Community-Based Inclusive Development (CBID) Congress, the 12th Paralympic Games and the 32nd South East Asian Games, which will be held in Phnom Penh in 2023.

They were also present at the Disability Action Council at the Ministry of Social Affairs, Veterans and Youth Rehabilitation on World Disability Day.



Access to water for a family affected by the disease

- World Leprosy Day was celebrated on 27 January in the village of Traeung, Kampong Cham, with the participation of 52 people affected by leprosy. CIOMAL provided each person with 50kg of rice.

- World Day for Disabled Persons was celebrated on 3 December in Koh Pich (Phnom Penh), with the participation of 69 people affected by leprosy.



Cow-banking for a family of beneficiaries



## 2. Brazil

In 2021, the WHO recorded 18,318 new cases of leprosy, making Brazil the second most endemic country after India. The prevalence of cases was 22,426 over the period.

The worst affected region is Mato Grosso, classified as hyperendemic with 15% of cases diagnosed.

CIOMAL, in partnership with the Curitiba-based Alliance Against Leprosy (AAL) institute, is focusing its efforts on skills transfer and training in new technologies to curb the disease. In 2022, four major projects were carried out :

### 3D shoes

Launched in 2021, this pilot project has led to the design of the first digitally 3D-printed adapted shoes for patients who have retained the scars of the disease (affected limbs, ulcers, wounds)



Cost of a pair: 250 USD, all expenses paid (appointment + dispatch within 10 days)

They replace conventional orthopedic shoes, which are often unsightly and whose weight (2kg per pair) triggers later physical problems (particularly in the hips). In partnership with AAL in Brazil, CIOMAL has teamed up with the manufacturer "Pés Sem Dor", a company present in all the Brazilian state capitals: patients' feet are scanned to ensure the best possible fit, the shoe is modelled on a computer and then produced on a 3D printer.

Thanks to these shoes, ulcers heal more quickly. Patients gain greater independence and self-esteem. The pair of comfortable, attractive shoes weighs just 500g, the usual weight of a pair of shoes.

In 2022, 10 volunteer patients were able to benefit from this pilot project and regain their mobility. In view of its success, the project has now been formalized and validated, and we are actively seeking funding to increase the number of beneficiaries.

### TECHansen project

This project aims to donate ergonomic equipment to patients with leprosy. By October 2022, over 2,000 assistive tools had been donated and distributed to over 300 patients in 17 Brazilian states (there are 25 states in Brazil). We are proud to announce that, in December 2022, this project received an award from the Ministry of Health as one of the three best projects (out of 52) for leprosy care in Brazil.

### Shoe workshops in Mato Grosso

Three complete workshops were carried out with a multidisciplinary team trained by Dr Susilène Tonelli Nardi, epidemiologist and consultant for AAL. These 12-hour theoretical and practical courses are offered and followed by fortnightly reviews of clinical cases presented by project professionals.



Beneficiaries of 3D shoes

### Telemedicine

The telemedicine platform, approved by Brazil's Federal Medical Council, has been in operation since January 2023. It will enable patients to consult healthcare professionals specializing in Hansen's disease from a distance. The aim of this platform is to facilitate the detection of new cases and to provide diagnosis and therapeutic advice. In Mato Grosso, 8 towns have already signed up and will follow the pilot project for 6 months.



### 3. Mauritania

According to the country's official statistics, 320 people are diagnosed each year in Mauritania, particularly in the Nouakchott region.

Although the figures cannot be verified, due to the lack of a census and qualified staff in the field, they are sufficiently alarming for CIOMAL to have decided to get involved in socio-economic reintegration projects in partnership with the Mauritanian Association for People Handicapped by Leprosy (AMPHL).

AMPHL is a founding member of the Federation of Associations for the Disabled, which brings together some 43 associations across the country.

#### Merchant shops

This project, initiated in 2022 by Prof. Francis Chaise, a surgeon with the French association of the Order of Malte, has led to the construction of three shops, the rental income from which is used to meet the needs of destitute families affected by leprosy. Located to the east of the city of Nouakchott, the shops were inaugurated in January 2023, on World Leprosy Day.

The rent from these shops will provide for the needs of 4 families, while 20% of the funds raised will go to AMPHL to supervise the premises.

#### Cost of building a shop :

€4,500

•

Rental value: €200 / year

#### Impact :

emergency aid for 4 families affected by leprosy

#### World Leprosy Day

During the ceremony for the 70th World Leprosy Day, organized by AMPHL, the Mauritanian television was able to interview H.E. Ambassador Karl de Mandat Grancey, ambassador of the Order of Malta to Mauritania, who thanked CIOMAL for funding the shops belonging to AMPHL. In the presence of the Secretary General of the Ministry of Health of Whali, Prof. Francis Chaise, the mayor of the district, as well as various dignitaries and families of leprosy sufferers, this day saw the inauguration of the two shops as well as the distribution of bags of rice and bottles of oil to patients.



Official photo during the inauguration. Mrs. Carole Vann (2nd from the left) for CIOMAL



Computer-generated image of future stores



Medical visit to a beneficiary family





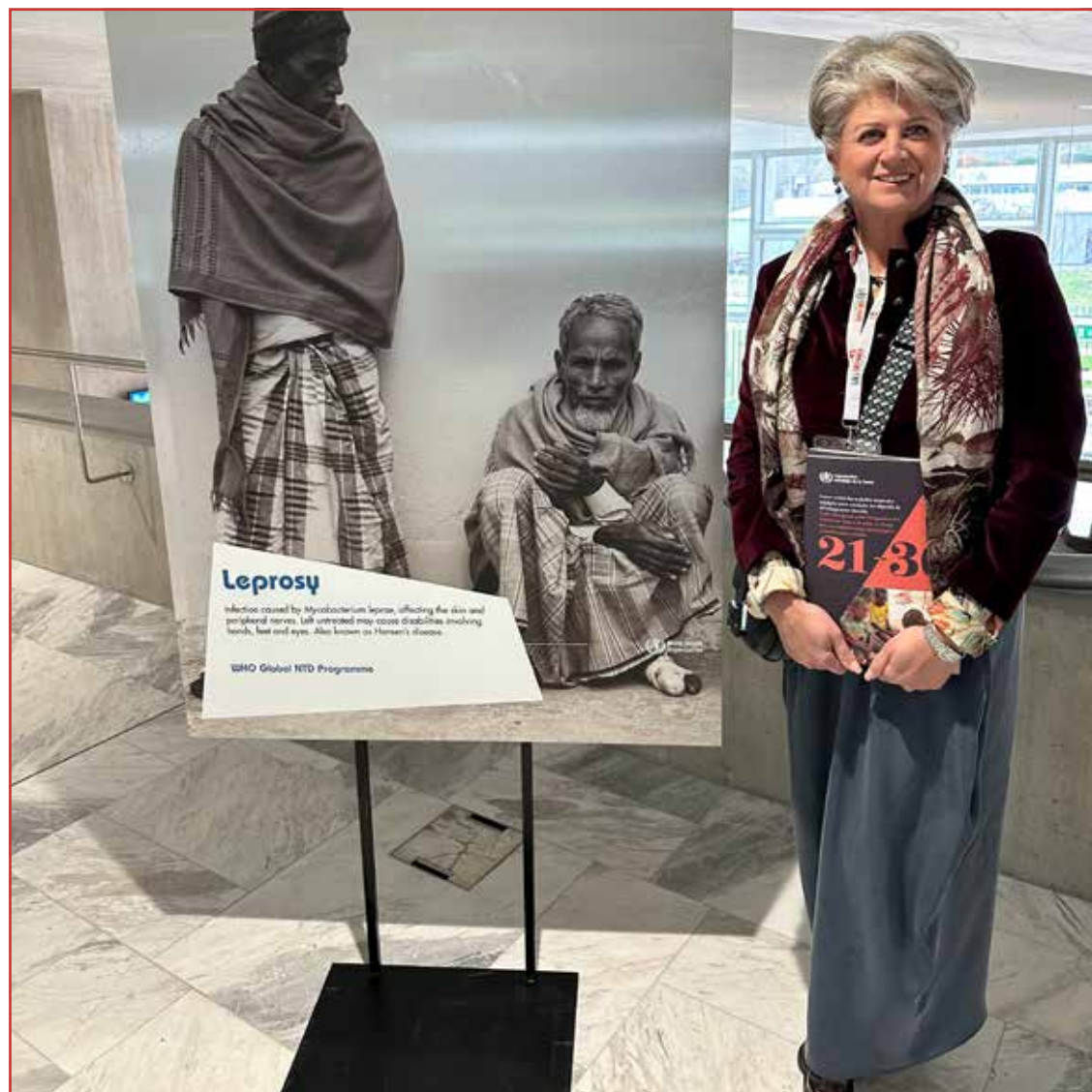
## INTERNATIONAL ACTIVITIES

### 1. International Leprosy Congress in Hyderabad, India

The 21st International Leprosy Congress was held in Hyderabad, India, from 8 to 11 November 2022. It brought together the world's leading experts to discuss the latest advances in research, protocols, new technologies and treatment of the disease. This year's event brought together over 1,000 participants from 56 countries in face-to-face sessions and 500 in virtual mode.

CIOMAL, with the sponsorship of our Brazilian partner (AAL), made a number of contributions. Dr Laila de Laguiche, founder of the AAL and a member of the CIOMAL Foundation Board, gave a world-exclusive presentation of a technological revolution: 3D-printed shoes for people whose limbs have been affected.

The conference provided an opportunity to meet leading names in international science and to share technological advances in the fight against the disease.



Dr Laila  
de Laguiche,  
leprologist and  
member of the  
Foundation's  
Board

### 2. European Congress of Dermatology, Milan

The 31st European Congress of Dermatology and Venereology was held in Milan from 7 to 10 September 2022. Considered to be Europe's biggest dermatology event, nearly 600 speakers in 170 sessions addressed a range of patient care issues.

This experience enabled CIOMAL representatives to meet numerous researchers, collaborate on future projects and establish a wide network.

The programme, which covered more than 50 topical issues, provided an opportunity to renew contacts with experts in the field of leprosy and to foster genuine scientific collaboration. It also helped to raise the profile of the CIOMAL Foundation among other NGOs.

### 3. Brazilian Leprology Congress, Vitoria

The 16th Brazilian Leprology Congress, held in Vitoria, in the state of Espirito Santo, Brazil, from 7 to 10 December, was sponsored by the Brazilian Leprology Society and supported by non-governmental organizations such as Alliance Against Leprosy (AAL) and the CIOMAL Foundation.

For the first time since the start of the Covid 19 pandemic, the conference brought together a large number of speakers. AAL, in partnership with CIOMAL, organized an interactive session called "Lunch-Box TECHansen", during which the Action TECHansen project was presented, which aims to donate assistive tools to patients with physical disabilities due to leprosy.

Dr. Laila de Laguiche also highlighted the cooperation project with the State of Mato Grosso, which focuses on adapted shoe workshops for people affected by leprosy.

### 4. 50th session of the UN Human Rights Council, Geneva

On 20 June 2022, Mrs Marie-Axelle Annicchiarico, a member of the CIOMAL Foundation's Executive Committee, addressed the 50th session of the UN Human Rights Council in Geneva.

She stressed the importance of sovereign states becoming more involved in the provision of adequate health facilities for people affected by leprosy and their families. She also encouraged States to set up a permanent advisory council in which representatives of people affected by leprosy or other neglected tropical diseases, represented by local associations or NGOs, should be included and rehabilitated.

This intervention raised public awareness of the importance of integrating consultation with people on the ground, at the heart of the problem, into the decision-making processes, for a sustainable and lasting solution.



## 1. Charity concert by the Orchestra des Nations, Geneva

On 10 May 2022, the CIOMAL Foundation invited its friends and benefactors to the Palais de l'Athénée for a benefit concert given by the Orchestre des Nations. Founder and director Antoine Marguier emphasized the international and humanitarian vocation of the orchestra, which is made up exclusively of top-level amateur artists. 12 soloists performed a program of works by W.A. Mozart, K.J. Lipinski, A. Jolivet and A. Dvorak.

These exceptional moments helped to forge ties of friendship between the Foundation and the Orchestre des Nations, which was celebrating its tenth anniversary. Dr Laila de Laguiche presented the first successes of the partnership between the Alliance Against Leprosy and the CIOMAL Foundation in the fight against leprosy.

We would like to express our gratitude to the musicians and their director who gave so generously of their time to organize and hold this concert



The Orchestra des Nations in concert

## 2. Benefactors' Dinner, Geneva

The first dinner for CIOMAL's Benefactors was held on 30 November 2022 at the Cercle de la Terrasse in Geneva, to bring together the generous private and institutional donors who are supporting the CIOMAL Foundation.

In the presence of representatives of the Sovereign Order of Malta and former CIOMAL Presidents, numerous donors and friends of the Foundation were able to meet and exchange ideas over a delicious autumn dinner. Dr Laila de Laguiche took the opportunity to present the Foundation's latest activities in Brazil, in particular the TECHansen assistive devices and 3D printed shoes.

The event continued late into the night and given the general enthusiasm, will be repeated next year.

## 3. CIOMAL 2022 cuvée

Following in the tradition of previous years, we repeated our CIOMAL cuvée.

In 2022, we collaborated with Domaine des Ménades in Anières, a family-run vineyard on the left bank of Lake Geneva, to offer a red Corès (a blend of three grape varieties: Gamaret, Garanoir and Merlot) in Magnum format.

As in previous years, our wine was a big hit with red meats, grilled meats and deer !



The producers of the CIOMAL 2022 Cuvée, Vincent and Alain Jacquier





*Bike for a scholarship student*



*Manufacturing of custom orthopedic insoles*



*A student revising*



*Restoration of a house for a family of beneficiaries*



## LIST OF BENEFACTORS

### Private donors

- Mr and Mrs Christian Adam-Adler
- Mr Danilo Albertini
- Mrs Geneviève Allimann
- Mr Jean-Pierre Amann
- Mrs Ursula Ammann-Schaerer
- Mrs Marielle André
- Mr Hans-Rudolf Annen-Schelbert
- Mr and Mrs Jean-Marc Annicchiarico
- Mr and Mrs Hervé Arot
- Mrs Charlotte Aubaret-Schumacher
- Mrs Barbara Audrin-Tessier
- Mr Guido Augsburgger Vivian
- Mrs Ignès Barchi
- Mr and Mrs Max Barouch
- Mr Marc-André Baschy
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- Mr Tiziano Belloni
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- Mrs Graziella Boggini
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- Mr Jacques Boissonnas
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- Mr Géo Borgeat
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- Mr Richard Brun
- Mrs Magda Brunella
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- Mr Philippe de Werra
- Mr Édouard de Yturbe
- Mrs Yolande de Ziegler
- Mrs Susanna Deidda
- Mr Graziano Del Fante



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- Mr Luc Denis-Rossier
- Mrs Maria Derber
- Mrs Alexandrine Déro
- Mrs Christiane Deruaz
- Mr Luc Desjacques
- Mr and Mrs Laurent Develle
- Mr Michel Ditisheim
- Mr Antun Divic
- Mr François Dominique Dominicé
- Mrs Françoise Donzallaz
- Mrs Hélène Dubuis
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- Mrs Manon Duez
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- Mr Michel Favre
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- Mrs Irene Ferrazzini
- Mr Marco Ferrazzini
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- Mr Nicolas Fleury
- Reverend Father Michel Fontaine
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