# SACTIVITY SREPORT





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Statut consultatif spécial auprès du Conseil économique et social de l'ONU



FEDERATION
GENEVOISE
DE COPERATION
Mettons le monde en mouvement

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# **CHAIRMAN'S FOREWORD**

As 2023 ends, a year marked by both victories and challenges, it is appropriate to reflect on the highlights of the CIOMAL Foundation's activities and its extraordinary achievements across four continents. 2023 was a year of growth in the Foundation's involvement with and support for people affected by leprosy, and we are grateful for having the opportunity to share a part of our journey with you.

The year began with the International Symposium at the Vatican on Hansen's disease. This brought together over one hundred professionals from around the world to explore the stigma and prejudice associated with leprosy. The CIOMAL Foundation reaffirmed the Order of Malta's commitment to initiatives in support of patients with leprosy—a commitment that goes back over 900 years—demonstrating its relentless dedication to this cause.

- Our activities in Cambodia this year focused on early identification of the disease, socio-economic rehabilitation for former patients and raising community awareness. Shoemaking activities have flourished, and discussions are underway to expand our work in this area into Vietnam. Individual support, ranging from developing 'cow banking' to providing school grants, has continued to improve lives and offer individuals new opportunities.
- In Brazil, we expanded our orthopaedic care and telemedicine initiatives to better serve patients with leprosy. Participation in the Brazilian Congress of Hansenology allowed us to develop our relationships with government officials and major stakeholders in the local health industry.
- In Mauritania, we maintained our presence, demonstrating our dedication to assisting patients with leprosy even in very distant locations.

In Geneva, our team worked relentlessly to raise awareness about the ongoing existence of leprosy. We have developed a new website to improve our communications, and we have used our special consultative status with the United Nations Economic

and Social Council (ECOSOC) to lobby for a more equitable allocation of resources in the fight against the illness.

Indeed, our team has expanded and has been fortunate enough to welcome new members with a passion for and dedication to our cause. Their invaluable contributions have increased our ability to work towards our goals with efficiency and compassion.

As we look towards the future, we are driven by the conviction that every action taken, every effort made, and every moment of solidarity makes a difference in the lives of the people we serve. Thanks to the loyal and generous support of all our benefactors, CIOMAL's teams are implementing our vision of a world without leprosy, and they are tirelessly pursuing, with tenacity, courage and dedication, our work with the more than 200,000 people newly diagnosed with leprosy every year who aspire only to regaining their health and living a dignified life.

CIOMAL's teams have been providing high-quality care for 65 years, and, in keeping with the spirit of the Order of Malta, they see the reflection of Jesus Christ in the hearts of those who turn to us.

On behalf of the Order of Malta's CIOMAL Foundation, I would like to express my deepest gratitude to all the private and institutional donors who supported our cause in 2023.

Together, we have achieved great things, and we will continue to make a difference.

Together, let's work towards the dream of a world without leprosy.



Mr



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# CIOMAL FOUNDATION'S OBJECTIVES

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CIOMAL is a Swiss foundation based in Geneva and is officially recognised as acting in the public interest. It has had special consultative status with The United Nations ECOSOC since 2018. Its main objective is fighting leprosy and its ensuing disabilities as well as all forms of exclusion linked to the disease, across the world.

The Order of Malta has been confronting the challenge of leprosy and its medical and socio-economic consequences for centuries; it has never ceased to work against the stigmatisation resulting from the disease.

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Indeed, CIOMAL was established in Geneva in 1958 with the goal of contributing to the disease's eradication through all appropriate means. 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 principal activities:

- Disease prevention (prophylaxis and early detection)
- · Rehabilitation for patients who have been cured

# To fulfil its objectives, the CIOMAL Foundation focuses its work on the following areas:

- Medical care involving polychemotherapy and rehabilitation, treatment for adverse reactions and their consequences as well as personalized therapeutic care;
- The prevention of disability through the training of healthcare staff and people affected by leprosy;
- Early diagnosis through active case-detection campaigns in the most affected regions;
- Socio-economic rehabilitation for cured patients through financial support for microenterprises, vocational training, house building or renovation, study grants and food aid;
- Awareness-raising campaigns to educate relevant populations and increase their knowledge about leprosy to stop its propagation, prevent severe disabilities and end the stigmatisation of people affected by leprosy and their families.



# The UN Sustainable Development Goals pursued by the CIOMAL Foundation



# Cease poverty and reduce inequalities



People affected by leprosy are among the poorest and most excluded populations. By helping to include them in networks of disabled people's associations and providing them with training, the project contributes to cease poverty and reducing inequalities.



#### **End food deprivation**

Stigmatised by the disease, people affected by leprosy often face exclusion and isolation. CIOMAL's teams identify the most destitute people and provide them with emergency food supplies and tools for self-sufficiency.



#### Ensure healthy lives and promote well-being for all at all ages

By developing sustainable and participatory mechanisms to ensure quality care, by increasing knowledge about leprosy among national health professionals and by supporting early detection, the project helps to ensure healthy lives and well-being for all at all ages.



8 DECENT WORK AND ECONOMIC GROWTH

#### Ensure quality education and sustainable economic growth

By funding scholarships for students by providing training to integrate people affected by leprosy into social schemes for people with disabilities, the project contributes to ensure equitable education and promotes opportunities for all.



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#### Achieve gender equality and empower women and girls

In every activity, the project pays particular attention to gender equality and participates in reintegrating women and girls affected by leprosy into their communities.



#### Strengthen partnership and implemented means to reach our objectives

Both in the field and in Switzerland, CIOMAL establishes partnerships to implement its objectives in close collaboration with local associations, national health systems, non-governmental organisations and States.

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# ON 31 DECEMBER 2023, THE BOARD OF TRUSTEES INCLUDED

Chairman: Mr. Thierry Zen Ruffinen

**Director of Finance:** Count Manfredo Radicati di Primeglio

**Trustees:** Prof. Philippe Jaeger

Dr Laila de Laguiche Mrs. Hélène Genillard Mr. Raymond Loretan

Mrs. Verena Vorwerk

Mr. Charles-Louis Notter

**Executive Committee:** Mrs. Marie-Axelle Annicchiarico

Mr. Thierry Zen Ruffinen

Count Manfredo Radicati di Primeglio

Mr. Hervé Arot

Head of Operations : Mrs. Carole Vann espace

**Head of Development:** avant le : Mrs. Olivia de Villaine

**Head of Public Relations:** Mrs. Alexandra Lucato



From left to right:

Mrs Olivia de Vilaine • Mrs Hélène Genillard • Mr Hervé Arot • Mr Thierry Zen Ruffinen • Me Charles-Louis Notter • Count Manfredo Radicati di Primeglio
Mrs Alexandra Lucato • Dr Laila de Laquiche • Prof. Philippe Jaeger • Mrs Verena Vorwerk • Mr Raymond Loretan

Not pictured: Mrs Marie-Axelle Annicchiarico • Mrs Carole Vann

Mettre un point après les titres



### A BRIEF HISTORY OF LEPROSY

Leprosy, commonly known as Hansen's disease, was one of the first diseases to be documented in human history

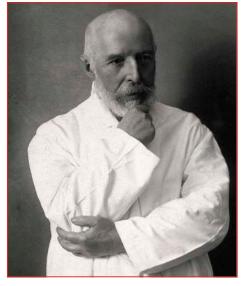
Leprosy was mentioned in ancient Egyptian, Chinese and Indian scriptures as early as 600 BC. It was often associated with divine punishment or a curse, and this led to the stigmatisation of sufferers. The disease was also mentioned in the Bible, particularly in the Old Testament.

In ancient Israel, leprosy was not only considered a physical disease but also a spiritual affliction, often associated with impurity. The Book of Leviticus contains detailed instructions on how to identify and isolate lepers.

During the medieval period, leprosy reached epidemic proportions in Europe and across the world. It spread through human migration and along trade routes, particularly during periods of exploration, the Crusades and European colonisation. It was particularly widespread in overcrowded urban areas, and the sick were often forced to live in leper colonies, isolated from the rest of society.

Only during the Renaissance and the early modern period did an initial understanding of leprosy begin to emerge, including some first attempts at treatment, although many misconceptions persisted. In the 19th century, scientists such as Gerhard Armauer Hansen identified Mycobacterium leprae as the cause of leprosy, leading to a better understanding and treatment of the disease

In the 20th century, the development of effective antibiotics such as dapsone, rifampicin and clofazimine revolutionised the treatment of leprosy, making it curable. As a result, the isolation of leprosy patients began to diminish, and the social stigma associated with the disease gradually reduced. Leprosy nevertheless remains a serious public health



Gerhard Armauer Hansen (1841-1912)

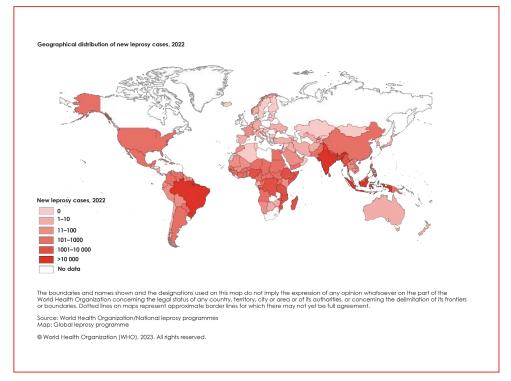
problem in some parts of the world, particularly in countries such as India, Brazil and Indonesia. Efforts to eliminate it are ongoing, focusing on early detection, multidrug therapy and reducing social stigma. Entities such as the World Health Organization have led efforts to eliminate leprosy as a public health problem. These efforts include providing free multidrug therapy to those affected, promoting early diagnosis through active case detection and combating social stigma through education and advocacy.

Leprosy has left a profound cultural legacy on humanity, influencing art, literature and religious beliefs. Stories of people affected by leprosy, such as Job in the Bible or fictional characters like Quasimodo in Victor Hugo's "The Hunchback of Notre-Dame", have inspired empathy and reflection on the themes of suffering, compassion and resilience.

# A BRIEF HISTORY OF LEPROSY

While significant progress has been made in understanding and treating the disease, leprosy still affects almost 200,000 new people every year. In addition, there are still more than a hundred laws worldwide that discriminate against people affected by leprosy, maintaining the significant societal stigma that can be an obstacle to obtaining treatment.

The CIOMAL Foundation's activities remain essential for the early detection of leprosy and for supporting thousands of families striving towards sustainable autonomy and reintegration into society.



Source: WHO – Weekly Epidemiological Record\_ September 15, 2023, 98th year

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# IV

# FIELD ACTIVITIES

# 1. Cambodia

CIOMAL established the National Programme for the Elimination of Leprosy in Cambodia following the Khmer Rouge's atrocities over 30 years ago. In collaboration with the Ministry of Health and the Ministry of Social Affairs, Veterans and Youth Rehabilitation, CIOMAL is responsible for delivering the country's Rehabilitation of Young People programme. CIOMAL established a rehabilitation and training centre for leprosy patients in Phnom Penh in 2000. Thanks to its work, cases of leprosy in Cambodia have sharply decreased in recent years, and the Foundation is primarily continuing its work in the following areas:

# The detection of and search for active cases (contact tracing)

à la ligne

Throughout 2023, CIOMAL conducted six campaigns in Battambang and Banteay Meanchey provinces, during which our teams visited 506 cured patients, 944 members of their households and 4'478 people in their immediate entourage. A total of 19 new cases were identified (15 men and 4 women). This low number is encouraging and underlines how our efforts are bearing fruit but must not slow down.

#### Awareness-raising campaigns

These awareness-raising campaigns aim to help relevant populations recognise the first signs of leprosy. They provide information about the disease's treatment, reduce levels of disability, lessen transmission rates, provide information about the health services available and, above all, combat the stigmatisation that exists in both urban and rural settings. In 2023, CIOMAL teams visited 480 families in 92 villages in 18 provinces.

#### Socio-economic rehabilitation

Since 2002, CIOMAL has been pursuing a socio-economic reintegration project as part of its activities to combat the consequences of leprosy and stigmatisation.



Detection campaign



Awareness campaign

This project responds to the social and economic needs of people affected by leprosy by encouraging and supporting their reintegration into society, providing them with a home, financial support to start a micro-enterprise or sponsorship for education.



# 1. Cambodia

#### During 2023, CIOMAL directly funded the following small projects

- CIOMAL's funding sponsored 63 students (3 university students, 36 secondary school students and 24 primary school students), allowing them to continue their education. School grants are awarded to young people directly or indirectly affected by leprosy, and they are guaranteed until the end of their studies. Grants cover school supplies, accommodation, transport and food. The Foundation's teams regularly visit grant beneficiaries and follow up with their families and teachers.
- Food aid was provided to 30 people affected by leprosy experiencing emergency situations, isolation
  or rejection by their communities.
- A first 'cow-banking' grant was given to a family to help them achieve sustainable financial independence.
- Micro-credits were provided to 31 people affected by leprosy to enable them to start a small business.
- Ten wells were drilled for isolated families to give them access to water. At the same time, filters were
  installed in 20 homes to provide access to drinking water. These installations have a huge indirect impact, affecting almost 140 people (each family has an average of 4 to 6 members).
- Our teams constructed 6 toilets, renovated 4 houses and constructed 2 new ones for families in need.
- Emergency food aid was provided for 30 families affected by leprosy and in extreme need.



House donation: before



House donation: after

## **TESTIMONIAL**

collecting cans and selling fish.

CIOMAL workers found Pich Nheob during a case detection campaign in the Kampot district of southern Cambodia, where the famous Cambodian pepper is grown. Pich Nheob and her husband lived in an unsanitary house, which CIOMAL later repaired. In 2017, she was treated with triple therapy and now has nearly no noticeable disease-related symptoms. She and her husband would go to local banquets to collect empty beer cans to sell for scrap. The locals' new-found goodwill, thanks to awareness raising, allowed them to cultivate a few vegetables on a patch of land, and during the rainy season, they caught fish and sold them at the market. In 2020, water became scarce, and restrictions related to the coronavirus generated major issues that led to a shortage of fish and tin cans. Because they were childless, Pich Nheob and her husband ended up in a precarious situation. They managed to overcome these challenging circumstances thanks to the cow banking system. A present the couple is still caring for their now-adult calves and has resumed their daily routine of



- A CIOMAL team assesses the living conditions of people affected by leprosy and the local availability of fodder.
- They search for one or two cows available in the community and then purchase them
- A contract is drawn up between CIOMAL and the beneficiary stipulating that the latter has the right and duty to look after the cows.
- Once a cow has given birth to two calves, the CIOMAL team takes one calf and allocates it to another person or family in need.
- The family and the cows belonging to them are regularly monitored.

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# 1. Cambodia

#### Raising awareness about self-care

By recognising the early signs and symptoms of leprosy, relevant populations and patients can apply appropriate treatments to their developing wounds to reduce the disability that may result. These self-care awareness-raising campaigns are organised on either an individual or group basis. Patients can learn the daily routines that will improve their quality of life. By 2023, 363 people directly affected by leprosy and 460 households had been trained in self-care and the prevention of wounds and injuries.

#### Training and capacity building

CIOMAL

As teaching people skills is a path to autonomy, COMAL puts a major emphasis on capacity building and training for all those involved in the fight against leprosy in Cambodia.

As a result, 94 former patients from the National Leprosy Association have benefited from training on the use of social networks, the development of a business plan, fundraising, preparing budgets and administrative organisation.

At the same time, the association's orthopaedic workshop continued to develop slowly but steadily, manufacturing 5 pairs of shoes especially adapted for patients, repairing 3 other pairs and creating 32 special shoes for clubfoot. Finally, a total of 610 staff from Cambodia's national health services benefited from capacity-building training in leprosy awareness.

#### Other activities

CIOMAL teams and members of the PAL association, as partners of Cambodia's network of associations for the disabled, participated in several meetings, conferences and workshops:

- The Asia-Pacific International Conference for Persons with Disabilities;
- The 5th Congress on Community-Based Inclusive Development in Phnom Penh, with a total of 250 participants from 22 countries in the Asia-Pacific Region;
- The 2023–2030 roadmap for the objective of zero leprosy;
- The Congress on Autism and Down Syndrome;
- The Global Technology Challenge for Youth with Disabilities for 2023 at the Disability Action Council
  and the Ministry of Social Affairs, Veterans Affairs and Youth Rehabilitation;
- World Leprosy Day was marked and celebrated in Traeung village (Kampong Cham province), with the participation of 60 people affected by the disease;
- The International Day for Persons with Disabilities was marked and celebrated in Koh Pich and organised by the Ministry of Social Affairs, Veterans and Youth Rehabilitation.



Recipient of an individual scholarship

# **Building a house:**

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around 7,500 USD (depending on the region)

# Financing an individual scholarship:

350 USD per student

Action	Impact	Number	Beneficiaries (direct and indirect)
6 contact-tracing cam- paigns in the Battambang and Banteay Meanchey provinces	Prevention and early detection	5,928 PAL* 19 new cases 480 families	People diagnosed, contact cases, families and neighbours
Awareness-raising cam- paigns	Prevention and awareness	92 villages 18 provinces	PAL*
Allocation of resources for academic training	Education and training	36 high schools 24 elementary schools	Elementary and high school students
	Education and autonomy	94	PAL*, recovered patients and family members
Loans for micro-enterprises	Financial autonomy	31	PAL* and families
'Cow banking' initiative	Financial autonomy and access to food	1	PAL* and families
Water-point mapping and the pipe system installation and maintenance	Access to clean drinking water, sanitation and hygiene	10	PAL*
Construction of boreholes and water wells	Access to clean drinking water and hygiene	10	PAL*
Distribution of water filters	Access to clean drinking water, sanitation and hygiene	20	PAL* households
Construction of toilets	Improved sanitation, perso- nal safety and dignity	6	PAL*
House construction	Protection, hygiene and social rehabilitation	2	PAL* households
House renovation & maintenance	Protection, hygiene and social rehabilitation	4	PAL*
Food bank	Emergency assistance for malnutrition	30	PAL*
Self-care training	Autonomy and remission	363 PAL* 460 Households	PAL* and family members
Training for national health services	Learning, networking and autonomy	610	National health services staff
Orthopaedic footwear production and repair	Autonomy, social reinte- gration and better mental health	36 pairs produced 3 pairs repaired	PAL* and recovered patients with a disability



# 2. Brazil

In Brazil, the number of new cases of leprosy - about 30,000 each year - is equivalent to the number of new cases of HIV-AIDS detected across the entire country or about half the number of new cases of breast cancer diagnosed in the population.

Mato Grosso, which is twice the size of France, is the state with the highest number of new cases, with 15% of all Brazilians diagnosed.

Most people affected by Hansen's disease live in poor socio-economic conditions and face significant social inequalities, with monthly family incomes below the minimum wage (USD 393). More than half of them nearly 15,000 people per year—go on to develop physical or functional sequelae due to their late diagnosis and the complications inherent in the disease.

In partnership with the Alliance Against Leprosy (AAL) Institute, CIOMAL focuses its efforts on five large-scale projects to fight leprosy and provide sustainable solutions for patients suffering from severe symptoms.

Nearly 5,000 people living in poor socio-economic conditions benefit from training and are prescribed special devices to improve their life during and after recovery.

#### The TECHansen project

This initiative aims to improve the quality of life of people with physical disabilities resulting from leprosy by donating assistive technology equipment and devices to patients across the country. Requests for assistance are made by the health professionals who accompany the treatment of patients affected by leprosy in 22 Brazilian states.



Delivery of TECHansen materials

The TECHansen project was one of the three highest-ranked initiatives in the "Mapping Successful Experiences in Leprosy" call for proposals and received an honourable mention from the Brazilian Federal Government and the Pan American Health Organization.

From its launch in 2021, thanks to the work of 135 health professionals, this project distributed 4,580 assistive technology tools to 517 patients affected by leprosy.

## FIELD ACTIVITIES

#### enlever le point final

Action	Impact	Numbers	Beneficiaries (direct and indirect)
Training for national health services	Learning, networking and autonomy	5,000 healthcare professionals trained in person.  200,000 community health workers received the TECHansen e-book, with instructions on assistive technologies	People diagnosed, contact cases, families, and neighbours
Self-care training	Autonomy, treatment, prevention and remission	380 patients	PAL
Orthopaedic footwear production and repair	Autonomy, social reintegration and mental health	356 new pairs 81 repairs	PAL
Donation of supply of support equipment	Autonomy, social reintegration and mental health	1,971	PAL, recovered patients and family members
Supply of technical equip- ment for diagnostic testing	Diagnoses	1,000 examinations 1,000 examinations stain- ing	PAL and contact cases
Actions and recommen- dations encouraging the publication of case reports in specialist journal	Dissemination of high-quality scientific information	2,000	Scientific health community
Information dissemination and awareness raising to fight against prejudice and stigmatisation in society	Dissemination of high-quality scientific information	40,089 people directly concerned by Hansen's disease	Society in general

\* PAL – Person affected by leprosy

#### The DOCHansen Project

This virtual platform connects general practitioners (family doctors) from all over Brazil, mostly working in primary care health units, with doctors experienced in the field of leprosy. This access to free video consultations makes it possible to establish diagnoses and set up appropriate treatments for complex cases.

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This initiative is a world first and truly pioneering. After a pilot project with general practitioners in Mato Grosso and Paraná, the platform is now available online via the AAL Institute's website, making its accessibility and visibility even greater.

"The DOCHansen project is a creative, sophisticated and complex option that protects the management of sensitive patient data, encourages inter-professional relationships and uses technology for the benefit of people critically affected by leprosy", emphasises Dr Laila de Laguiche, President of the AAL Institute and member of the CIOMAL Foundation Board.

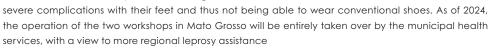


### 2. Brazil

#### The FEETHansen project

Thanks to the establishment of orthopaedic shoe workshops in endemic areas, adapted insoles and digitally manufactured shoes can now be distributed to isolated patients with impaired mobility. The shoes are produced using state-of-the-art foot, scanning technology that produces a mould using a 3-D printer. Shoes are, thus, customised according to the patient's pathology and specific needs.

In 2023, CIOMAL funded 20 pairs of digitally manufactured shoes for patients suffering from



« After eight years, I can walk again. I'm so happy, ». R.Z., 38 years old

« Après huit ans, je peux à nouveau marcher. Je suis si heureux. » R.Z., 38 ans.



# FIELD ACTIVITIES

# 3. Other activities \_\_\_\_\_

#### Vietnam

#### phrases trop serrées

CIOMAL started a new project in Vietnam in 2023 in collaboration with the Order of Malta, France. This involved financial support for an orthopaedic workshop, created in 2006 by a volunteer, for people with disabilities related to leprosy. Until 2020, the workshop had survived thanks to occasional help from foreign visitors, but the isolation caused by the COVID-19 pandemic had slowed down its activities. Thanks to CIOMAL's support, the workshop now has five qualified technicians. The localities identified are in the centre of the country, in the provinces of Gia Lai and Kon Tum, where there are currently 1,900 leprosy patients living in 37 villages. Among them, nearly 900 people require regular care for their feet, which often suffer from

In 2023, the workshop produced 808 pairs of sandals, 909 pairs of shoes for deformed feet and 501 pairs of moulded shoes for feet severely damaged by the disease.



Shoe workshop

#### Mauritania

ulcers.

The CIOMAL Foundation, in partnership with the Mauritanian Association for the Promotion of People Handicapped by Leprosy, financed the construction of three shops in the capital, Nouakchott.

The shops have allowed leprosypatients to find work in and benefit from a dispensary thus generating income to meet the needs of their families.



Shop in Mauritania

3D Shoe Beneficiaries

Scanner



# INTERNATIONAL INFLUENCE

# 1. International symposium on

Hansen's disease

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On 23 and 24 January 2023, an International symposium on Hansen's disease was held at the Vatican in the presence of numerous foundations, charitable associations, representatives of the World Health Organization (WHO) and organisations promoting sustainable human development, and distinguished professors, doctors and experts in the field. The CIOMAL Foundation was represented by Mr Thierry Zen Ruffinen, Count Manfredo Radicati di Primeglio and Dr Laila de Laguiche.

∕lr. Dr.

Discussions took place on the progress made since the previous symposium in 2016 and the challenges that remain. Synergies have made it possible to identify new avenues of collaboration and financing in Colombia, Nepal, Brazil, Benin, Mauritania and Cambodia.

#### CIOMAL

The CO'MAL Foundation's President presented the decisive actions taken by the Order of Malta on behalf of people affected by leprosy over the past 900 years. He reported on the best practices implemented by the CIOMAL Foundation since its creation in 1958 and shared his dream "of ceasing activities by 2050 because leprosy will have been eradicated worldwide" point final

At the end of this event and in the run-up to World Leprosy Day, the participants signed a Global Call to "Leave No One Behind" with the goal of ending the stigmatisation of and discrimination against people with leprosy.





Mr. Thierry Zen Ruffinen at the Global Appeal with Mr. Yohei Sasakawa, Chairman of the Sasakawa Foundation and WHO Goodwill

Ambassador for the Elimination of Leprosy

# INTERNATIONAL INFLUENCE

# 2. World Health's Organisation meeting on neglicted tropical diseases

The World Health Organization (WHO) held its first global meeting on skin-related neglected tropical diseases (NTDs) in Geneva from 27 to 31 March. These still affect 1.8 billion people and account for half of all the NTDs worldwide. With the theme of "Integration for Greater Impact", nore than 1,300 participants from 86 countries attended the event, including Dr Laila de Laguiche, who is a leprologist and member of the Foundation Board.

The meeting's conclusions underlined the importance of national leadership for better training, increased funding and more strategic advocacy, as well as operationalising new diagnostic tests, more active patient engagement and better training for frontline health workers.

# 3. Brazilian congress of Hensenology, in Cuiaba



Leprology Congress

The 17th Brazilian Congress of Hansenology was held in Cuiaba, Brazil, from 20 to 21 September. It was sponsored by the Brazilian Society of Hansenology and supported by non-governmental organisations such as the AAL Institute and the CIOMAL Foundation.

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During the Congress, the AAL Institute presented its projects and demonstrated all the assistive technology devices developed by the TECHansen project, the digitally manufactured shoes produced by the FEE-JHansen project and the information available on the DOCHansen platform.

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Represented by <u>Dr Su</u>silene Nardi, the Institute also hosted a panel discussion on disease prevention and healthcare activities in Brazil. The panel comprised other organisations such as the Brazilian branch of Netherlands Leprosy Relief and the Movement for the Reintegration of People Affected by Leprosy.



# **ACTIVITIES IN GENEVA**

# 1. The United Nations Human Rights council

Within the framework of the 52nd session of the United Nations Human Rights Council, CIOMAL, represented by Mr Hervé Arot, Member of Trustees, reiterated its proposal to federate the public authorities, private sector actors and not-for-profit organisations involved in conducting socio-economic rehabilitation projects benefitting people affected by leprosy. This was the subject of his statement during the meeting organized on 27 February 2023 between the President of the 77th General Assembly of the United Nations, Mr Csaba Korösi, and civil society.

#### Mr. Hervé Arot

On 23 June, Mr Arot spoke again at the 53rd session of the United Nations Human Rights Council as part of the interactive dialogue with the United Nations Special Rapporteur on discrimination against persons with leprosy. The CIOMAL Foundation, thus, supported the renewal of the Special Rapporteur's mandate and the promotion of a candidacy from a person who had been affected by leprosy. In addition, the CIOMAL Foundation suggested that a global assessment of the funding available for the fight against leprosy be carried out to optimise its allocation to the countries classified as priorities by the WHO and among the least developed according to United Nations criteria.

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# 2. Benefactors dinner

Nearly fifty institutional and private contributors who generously support the Foundation and its initiatives came together for the second annual benefactors' dinner "Le Cercles des Bienfaiteuts", held on 29 November 2023 and hosted at the prestigious Ritz-Carlton Hotel de la Paix, in Geneva.

Dr.

In the presence of representatives of the Sovereign Order of Malta and members of the CIOMAL Foundation's Board, our guests sat to a delicious autumn dinner and, most importantly, listened attentively to a presentation on Mr Zen Ruffinen's working visit to Brazil in September alongside Dr Laila de Laguiche. He summarised the Foundation's latest activities in Mato Grosso, including information on the TECHansen support tools and added value provided by 3-D printed shoes. He also described the promising advances made in East Asia.

The CIOMAL Foundation would like to take this opportunity to reiterate its deepest thanks to Mr Antoni von Planta, the hotel's General Manager, who's personal involvement contributed greatly to the event's success.

# 3. "Course de l'Escalade"

Our President, Mr Zen Ruffinen teamed up with loyal donors, friends, and staff of the Foundation to participate to the 45th Escalade race in Geneva in December 2023. This was CIOMAL's first event around sports and this emblematic was the perfect opportunity.

This occasion gave the CIOMAL Foundation extra visibility in its hometown, raising awareness about our work and activities around the world, as well as bringing our runners together in friendly surroundings.

# VII

# TRAVEL NOTEBOOK

Mr.

Dr.

In September 2023, the Board's President, Mr Thierry Zen Ruffinen, travelled to Brazil, where he joined Dr Laila de Laguiche to assess CIOMAL's projects three years after their initiation.

Covering almost 24,000 kilometres in nine days and travelling across five states, he met with the Order of Malta's ambassador H.E. Franz Graf von Schoenborn, Mr Rafael Greca, Mayor of Curitiba, Representatives from the Order of Malta based in Brasilia, as well as numerous Brazilian influential individuals, all in support of CIOMAL's initiatives.

In Paraguarí, a town outside Curitiba, Mr Zen Ruffinen encountered some former patients. The town was built on the site of a former leper colony, where individuals from Curitiba who had been diagnosed with the disease had previously been forcibly imprisoned and locked away from society. Several former patients testified about the illness's after-effects, which include deformed fingers, a collapsed nasal cavity, 'leprous feet' due to peripheral neuropathy that results in significant restrictions to mobility, as well as total insensitivity across substantial parts of their bodies. The most significant issue in their daily lives, however, was their feeling of exclusion and alienation from society.

Paraguarí's dermatological hospital is located on the site of the Saint Roch leper colony, which once housed up to 1,400 patients. In addition to producing assistive equipment for patients, the hospital's leprology unit now also has a physiotherapy department. About 300 people still undergo treatment annually, indicating that leprosy is far from being completely eradicated.

Testimonial: Dide is a Caboclo, an inhabitant of Amazonia and a descendant of Amerindians. This is her story

"With both my parents having leprosy, I found myself exiled 1,000 kilometres from my place of birth and, in around 1960, aged seven, I was entrusted to three families in the region for whom I became a sort of unpaid maid. But at least I was given the assurance of food, a roof over my head and the chance to get a school education. But that last part of the deal was never honoured, and nobody ever protected me from the rapes I suffered in one of those families."

Dide only found the strength to talk about all of this after she was 20 years old, when the authorities came to snatch away her own daughter, "aged 3 months and 22 days old", to put her up for adoption after Dide herself had been diagnosed with leprosy.

The visit moved on to the Federal University of Paraná's engineering department, with which the AAL Institute collaborates closely to create prostheses and orthotics. A highly qualified team consisting of academic medical specialists, PhD candidates and master's students in medicine analyse each patient's relevant ergonomic needs using tools like thermography, 3-D scanning, artificial intelligence and additive manufacturing.



# TRAVEL NOTEBOOK

A video conference was held in Cuiaba, the capital of the state of Mato Grosso, to follow up on two shoemaking facilities financed by CIOMAL in remote areas. This was followed by the Brazilian Congress of Hansenology, attended by a CIOMAL delegation including Mr Zen Ruffinen and Dr Laila de Laquiche.

In a nation where financial compensation is hard to come by because civil society is hesitant to acknowledge the suffering of thousands of victims, seeking and obtaining restitution remains a huge challenge. Therefore, the psychological, technical and financial help that charitable institutions can offer patients is especially crucial. Even though leprosy treatments and diagnoses have improved significantly in recent years, discrimination persists and affects many patients' lives. If any conclusion had to be made after these experiences, it would be that persisting and persevering in our activities is paramount.





Mr. Thierry Zen Ruffinen and Dr. Laila de Laguiche



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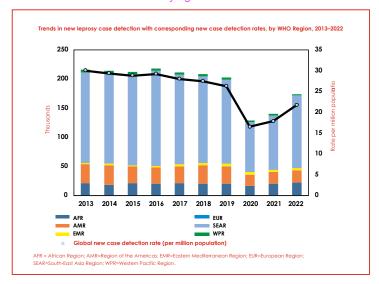
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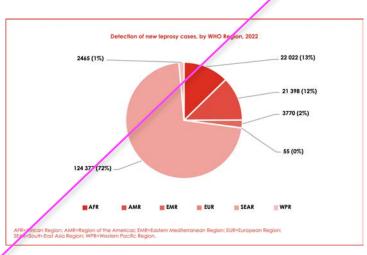
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