ACTIVITY REPORT

2021

ORDER OF MALTA
SWITZERLAND
CIOMAL FOUNDATION

ORDER OF MALTA
SWITZERLAND
CIOMAL FOUNDATION

Since its creation in 1958, the CIOMAL Foundation has kept up with the times. It has enjoyed special consultative status with the United Nations Economic and Social Council since 2018 and actively supports the following initiatives:

Global Partnership for Zero Leprosy

FEDERATION GENEVOISE DE COOPERATION
Mettons le monde en mouvement

Special consultative status with the
United Nations Economic and Social Council

ECOSOC
Economic and Social Council

OBJECTIVES OF THE CIOMAL FOUNDATION

To fight leprosy and all forms of exclusion and disability throughout the world, in accordance with the secular tradition of the Order of Malta.

For centuries, the Order of Malta has faced leprosy and its medical and socio-economic consequences and never stopped fighting the stigma-filled disease.
To pave the way towards its elimination, the Order of Malta created CIOMAL in 1958, which became a Swiss not-for-profit foundation in 1999 and took the name of the Order of Malta's CIOMAL Foundation (Order of Malta's International Campaign Against Leprosy).

In its projects today, the CIOMAL Foundation focuses on two main approaches:

- **treating the disease (prophylaxis, early detection); and**
- **rehabilitating the persons affected.**

As of 31 décembre 2021, the Foundation Board was composed as follows :

Chairman :	M. Thierry Zen Ruffinen
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Members :	Prof. Philippe Jaeger
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	M. Charles-Louis Notter
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	Mme Marie-Axelle Annicchiarico
	M. Hervé Arot
	M. Alexandre Zanetta
Operational Manager :	Mme Carole Vann
Development Officer :	Mme Lauren Bouvier

From left to right : *Mr Hervé Arot, member of the Management Committee - Ms Lauren Bouvier, development officer - Pr. Philippe Jaeger, member of the Foundation Board - Ms Verena Vorwerk, member of the Foundation Board - Mr Thierry Zen Ruffinen, Chairman - Ms Hélène Genillard, member of the Foundation Board - Pr. Laila de Laguiche, member of the Foundation Board - Mr Charles-Louis Notter, member of the Foundation Board - Ms Marie-Axelle Annicchiarico, member of the Management Committee - Count Manfredo Radicati di Primeglio, Treasurer.*

Absent : *Mr Raymond Loretan, member of the Foundation Board - Ms Carole Vann, operational manager.*

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- Exhibition “DIVERS ÉGALES UNIS, an artistic look at the UN universal values” at the Rath Museum
- Benefit evening of the Swiss-Turkish Association
- CIOMAL 2021 Cuvée
- Solidarity initiative
- 47th session of the United Nations Human Rights Council

23-31	THANKS

- Donors
- Solidarity raffle partners

Le CIOMAL acts at several levels :

1. Medical care and rehabilitation :

polychemotherapy (PCT) treatment, treatment of the leprosy reaction and consequences of the disease; physiotherapy.

2. Disability prevention :

through trainings for healthcare workers and persons affected by leprosy.

3. Early detection :

through active case searches in the most affected areas.

4. Socio-economic rehabilitation :

financial aid for micro-businesses, professional training courses, home building or renovation, scholarships, and food aid.

5. Awareness campaigns :

specific campaigns aimed at stopping the contagion as well as reducing severe disabilities and stigma against the persons affected by leprosy and their relatives.

FOREWORD

CIOMAL is a Swiss not-for-profit foundation based in Geneva. Its main objective is to fight leprosy and all related forms of exclusion or disability throughout the world.

Kout Sithorn, beneficiary of the CIOMAL Foundation in the province of Kompong Thom.

A WORD FROM THE CHAIRMAN

An evil that spread terror,
an evil that Heaven in its outrage
Devised to punish crime on Earth…

This is **leprosy** (since we must call it by its name)

If La Fontaine had written his fable "The Animals Stricken by the Plague" nowadays, he very well might have chosen leprosy to illustrate his critique of hypocrisy and outrage at a justice system in the service of the powerful.

The CIOMAL Foundation of the Order of Malta has been fighting leprosy in Cambodia for 27 years, together with the local authorities and several international partners. Thanks to CIOMAL's action and the decreasing prevalence of the disease, the healthcare activities of the rehabilitation centre for persons affected by leprosy (which opened in 1999 in Phnom Penh) were transferred to the Cambodian government in 2020.

The strict lockdown imposed on the Cambodian people because of Covid-19 has of course not made it easier for us to assist those affected by leprosy. A few initiatives had to be postponed but our crucial activities of contact tracing and awareness campaigns have continued and reached thousands of people. We were able to maintain our socio-economic rehabilitation as well as treatment and training activities: nearly 300 families were visited by our teams and over 100 persons affected by leprosy received training on wound and injury prevention as well as prophylaxis rules. Thanks to a partnership with a local organisation, a few dozen former patients were trained on administrative acts related to daily life or self-employed business.

In addition, CIOMAL has contributed to improving the deplorable sanitary conditions (which are vectors of several diseases) in which the poorest persons affected by leprosy live. We have financed the building of latrines, the renovation and building of homes, as well as the drilling of wells for drinking water.

CIOMAL has devised the concept of "cow-banking" by loaning cows to former leprosy patients aspiring to become farmers.

Some persons affected by leprosy have ended up in a desperate financial situation because of the confinement. In order to provide them with concrete help, CIOMAL devised the concept of "cow-banking" by loaning cows to former leprosy patients aspiring to become farmers.

In Brazil, the new cooperation with the Alliance Against Leprosy Institute has unfolded in accordance with plans, particularly in the State of Mato Grosso. Two orthopedic shoe-making workshops have received equipment thanks to the CIOMAL Foundation in Alta Floresta and Tangará da Serra, while a third one will open soon. The 3D printers used to manufacture some of the prostheses and orthoses have turned out to be high performing, as their beneficiaries have testified. We are also delighted to announce the impending launch of a telemedicine platform, which holds much promise in such a vast country.

In Geneva, the enthusiasm stirred by the CIOMAL Cuvée and the solidarity initiative in 2020 has encouraged us to renew both projects in 2021. CIOMAL's amazing donors were also able to enjoy an exclusive visit to some of the works in the United Nation's art collection in September. Also, at the 47th session of the Human Rights Council, CIOMAL had the opportunity to engage in an interactive dialogue with the Special Rapporteur on leprosy and make a noteworthy statement to encourage the establishment of national special organisations focusing on persons affected by leprosy and their families, by ensuring economic inclusion through microcredit, adequate housing, and scholarships.

Finally, I take this opportunity to express my very special thanks to Madame Inci de Boccard, Chairwoman of the Swiss-Turkish Association, for organising their annual ball for the benefit of CIOMAL. This magnificent event was held in the very salon of the Beau-Rivage Palace, where the Treaty of Lausanne was signed on 24 July 1923 to recognise Turkey as a sovereign state with Ankara as its capital.

At the institutional level, the Foundation Board has bid adieu to Dr. Henri Perroud, who has served CIOMAL with great dedication for six years, and welcomed Dr. Laila de Laguiche, dermatologist and internationally-renowned leprologist. Management was also consolidated by Ms Marie-Axelle Annicchiarico, who will put her intelligence, wisdom, kindness and enthusiasm in the service of our cause.

Despite CIOMAL's sustained efforts for almost 65 years, leprosy still infects 200,000 people every year. The loyal and generous support of all willing people to CIOMAL is incredibly valuable as it contributes to our vision of a world without leprosy. The material generosity of CIOMAL's private and institutional donors is received as a blessing by the beneficiaries that our valiant teams have been able to help. We could not do it without the loyalty of all our friends.

Dear friends and generous donors, I am extending here the immense gratitude of the Foundation's Board.

Dream with us,
join us,
and support us:
www.ciomal.org!

Thierry ZEN RUFFINEN
Chairman

ACTIVITIES IN CAMBODIA

CIOMAL has been fighting leprosy in Cambodia for 27 years. In partnership with the National Leprosy Elimination Programme (NLEP) established by the Cambodian Ministry of Health and the Ministry of Social Affairs, Veterans and Youth Rehabilitation, CIOMAL opened a rehabilitation and training centre for Persons Affected by Leprosy (PAL) in Phnom Penh in 1999. Thanks to the efficacy of its action on the ground, the centre was handed over to the Cambodian authorities in 2020.

In 2021, due to the spreading of Covid-19, some of our activities in Cambodia had to be postponed because of the confinement imposed on some provinces.

Starting in 2022, CIOMAL's other activities will continue, including contact tracing, awareness-raising, capacity-building, and socio-economic rehabilitation.

1. CAPACITY-BUILDING

Self-management is at the core of many projects across the world so persons affected by leprosy learn how to manage their disabilities and prevent any deterioration of their condition.

CIOMAL organises a daily follow-up at the individual or group level, including :

• the use of prevention methods during daily activities (for example, using a rag to handle a hot pan or frequent eye blinking to avoid dryness);

• the inspection and treatment of wounds and infections that are no longer felt because of nerve lesions;

• the oiling and care of hands and feet to avoid skin dryness and cracking;

• and stretching exercises to prevent stiffness and contractures.

• 110 persons affected by leprosy received training on self-treatment and wound and injury prevention ;

• 166 healthcare workers received capacity-building training on leprosy awareness-raising.

In addition, CIOMAL supports APAL, a Cambodian association that was able to provide in 2021 various trainings on :

- budget management;
- inventory management;
- web development and opening a bank account for PAL;
- management and use of social media;
- information on the Law on the protection and promotion of the rights of persons with disabilities

.

• 115 people affected by leprosy were able to benefit from these different trainings.

Yoern Suy, CIOMAL beneficiary learning to treat his wounds.

In 2021, CIOMAL continued supporting :

- **41 students ;**
- **65 PAL through food or economic assistance ;**
- **7 latrines were built for PAL in seven provinces ;**
- **7 new homes were built or renovated for PAL ;**
- **2 wells were drilled for two PAL in the provinces of Odor Meanchey and Siem Reap.**

New activity :

"Cow-Banking"

Following the outbreak of Covid-19, some persons affected by leprosy (PAL) ended up in a desperate financial situation. In response, CIOMAL's team decided to start "cow-banking."

CIOMAL provides cows to PAL. After the cow gives birth to two young calves over two years, the PAL are able to keep the two calves while returning the cow to CIOMAL, who will then loan it to other PAL.

2. ACTIVE DETECTION

Throughout the past year, the second round of active case searches through contact tracing has continued and reached thousands of people. Two campaigns were carried out in the provinces of Rattanakiri and Kampong Thom, in collaboration with the National Leprosy Elimination Programme (NLEP). Thanks to these campaigns, 9 adults and 4 children were diagnosed.

This low detection level of new cases is a result of the successive lockdowns due to Covid-19 but we were happy to note that the awareness-raising and treatment efforts made by CIOMAL's staff have continued to bear their fruits.

In addition, the prescription of a prophylactic medicine to people who are in close relationships with persons affected by leprosy has been particularly effective.

3. SOCIO-ECONOMIC REHABILITATION

In 2002, CIOMAL created a Socio-Economic Rehabilitation (SER) project in the wider context of its fight against leprosy in Cambodia to emphasise the reintegration of persons with leprosy who have been isolated within their communities.

This is a way for CIOMAL to ensure that all former patients receive follow-up and support at the social and economic level, for instance by providing them with shelter, financial aid to start a small business, or education sponsorship. The latter can take the form of professional training or primary, secondary or university education.

Student benefitting from a scholarship.

These scholarships are intended for youth who have leprosy or live in a family with a member affected by leprosy. CIOMAL seeks to support students until the end of their studies, including through close follow-up. The team visits beneficiaries regularly as well as their families and teachers. Scholarships are granted to students for study materials, accommodation, and food.

4. AWARENESS CAMPAIGNS

Leprosy awareness campaigns are crucial to eliminate the disease and its consequences, to put an end to the stigmatisation of those affected and their families, and to raise awareness in rural and urban areas.

Awareness campaigns also help people learn to recognise the first signs of leprosy, provide information on the complications and treatment of the disease, reduce its transmission, prevent disabilities caused by leprosy, and increase general knowledge about this scourge.

In 2021, a CIOMAL team visited 270 families in 42 villages in 10 provinces.

Awareness-raising helps people learn to recognise the first signs of leprosy and reduce its transmission.

5. ADVOCACY / LOBBYING

3rd from the left: Carole Vann, operational manager, with the Association of persons affected by leprosy.

At CIOMAL's instigation, the village of Traeung in the province of Kampong Cham saw the gathering of over 50 persons affected by leprosy on 31st January for the International Day of Persons with Disabilities. Each person received 50kg of rice as emergency relief for persons prevented from earning a living due to the lockdown.

In addition, CIOMAL's staff received a training in the context of the strategic plan to eliminate leprosy 2022-2030 as well as the revision and renewal of the government framework agreement with the Ministry of Social Affairs.

Located in the heart of Brazil, south of the Amazon rainforest, the State of Mato Grosso has a vast surface area of 900,000 km² and a population of 3.5 million inhabitants spread out across about a hundred municipalities.

Localisation of shoe sole manufacturing workshops.

ACTIVITIES IN BRAZIL

In 2020, according to WHO data, Brazil diagnosed 27,396 new cases of leprosy (Hansen's disease), including 1,545 in children under 15, which makes it the world's second most affected country after India.

The region of Mato Grosso is the most impacted in Brazil and is classified as hyper-endemic, with 15% of the country's new leprosy cases, which represents about 4,000 new cases every year.

1. INTRODUCING OUR LOCAL PARTNER

The Alliance Against Leprosy (AAL) Institute is headquartered in Curitiba, in the State of Paraná, and is a non-profit organisation that is internationally active and combines science, education and philanthropy to fight leprosy. The organisation was founded by Dr. Laila de Laguiche, dermatologist and leprologist specialised in tropical diseases with over 20 years of experience. The AAL Institute stood out since its founding for its training programmes for more than 800 healthcare professionals active in the field of leprosy. Several actions, including on social media, were carried out in partnership with specialised medical authorities such as the Brazilian Society of Hansenology, whose board of directors Dr. Laila de Laguiche was a member of from 2018 to 2020. Dr. Laila de Laguiche joined the CIOMAL Foundation's Board in 2021.

The partnership project between the CIOMAL Foundation and the AAL Institute is mainly focused on transfer of competencies and training.

Dr. Laila de Laguiche (centre), visit to the Reference Centre for the treatment of leprosy in the State of Mato Grosso, CERMAC.

Activities in Brazil

2. A WORD FROM DR. LAILA DE LAGUICHE

Hansen's disease is a chronic infectious disease caused by the Mycobacterium leprae, a bacteria that multiples slowly and it may take five to ten years for symptoms to appear. The pathology mainly affects peripheral nerves and is often associated with skin lesions and a loss of sensation, which can induce irreversible damage in the hands, feet and eyes. Leprosy is contagious and is transmitted through respiratory droplets, but 90% of the population is immunised. In other words, the disease only manifests in 10% of the contaminated population which has an immunological predisposition that is genetically determined. This results in whole families suffering from the disease in a transgenerational way, with poverty, social isolation, and unsanitary living conditions perpetuating such transmission.

This scenario is exacerbated by the difficulty for healthcare professionals to identify the disease, the scarcity of accessible diagnostic technologies, and the impossibility to grow the bacteria in laboratories. Combined with a lack of information and widespread prejudice, these factors contribute to late diagnosis, which results in an exponentially higher risk of irreversible damage.

WHO classifies Hansen's disease in the list of neglected diseases, which are characterised as infectious pathologies that mainly affect populations living in extreme poverty.

Few doctors are prepared to face this disease, which leads to a significant underreporting of cases. Prejudice and disinformation mean that patients hide and live in social isolation, which thwarts a favorable outcome for a disease that is now completely curable. WHO has studied and implemented chemotherapy and immunoprophylaxis regimens that can be promising for relatives and other persons living with patients still remaining without treatment so they avoid developing leprosy.

Although this is an age-old disease that goes back to Biblical times, Hansen's disease remains an issue nowadays and has a serious impact on the poorest people. Every year, about 200,000 people are newly diagnosed with the disease and the most affected countries are India, Brazil and Indonesia, which still make up about 80% of all cases recorded nowadays. In Brazil, Hansen's disease is a compulsory notification disease and it must be treated exclusively within public healthcare networks. It is maybe for this reason that numbers matter so much, as illustrated by the lack of data that can occur in so many other countries.

Changing the global terminology of Hansen's disease to lessen prejudice towards this population has failed to significantly change the lives of patients who still live with the disease. About 20 countries still have discriminatory laws against those patients and the United Nations, as represented by its Special Rapporteur Ms Alice Cruz, strives to eliminate this form of discrimination.

In 2021, CIOMAL signed a partnership with the Alliance Against Leprosy (AAL) Institute. In cooperation with the Department of Health of the State of Mato Grosso, CIOMAL and AAL intend to :

1. Establish a network of orthopedic shoe adaptation workshops in order to reduce the number of patients showing a degree of physical disability with foot deformities (i.e. currently about 50% of patients), which results in the impossibility of professional activities as well as personal suffering.

2. Build a digital teleconsultation network between professionals specialised in Hansen's disease and doctors located in the State's most remote areas in order to foster better quality care as well as quality medical knowledge transfer.

Dr. Laila de Laguiche (left) at the Reference Centre for the treatment of physical disabilities in Mato Grosso.

Specialised teleconsultation is in its final adjustment phase and will start in April 2022. In October 2021, two shoe adaptation workshops were set up in the municipalities of Tangará da Serra and Alta Floresta. A 12-hour shoe adaptation class was provided and gave both theoretical and practical training. The workshops are already operational to promote their services with the local population.

5% of persons cured from leprosy still have disabilities that prevent them from using standard orthopedic shoes or soles, which forces them to have specialised shoemakers make them customised shoes, a process that is particularly long and expensive.

With CIOMAL's financial support, a pilot project was carried out to study the feasibility of digital shoe-manufacturing. The shoes are created by making 3D scans of patients' feet and printing them on 3D printers. This means they are custom made to the millimetre.

Dr. Laila de Laguiche (left) at the Reference Centre for the treatment of physical disabilities in Mato Grosso.

This service is already offered for neuropathic (diabetic) feet but it is a world first for leprosy patients who suffer from severe disabilities. The patients who received these shoes have seen a dramatic improvement of the scarring of their wounds, in addition to recovering strong self-esteem as well as a social life.

These "digital" shoes look the same as normal shoes and they will be presented at the next International Leprosy Congress in November 2022, in Hyderabad, India.

We are confident that we can make a difference in a country as seriously affected by leprosy as Brazil, by taking advantage of unprecedented technological progress and strengthening healthcare networks and knowledge transfer for quality humanised healthcare.

Dr. Laila de Laguiche
Foundation Board member.

1. EXHIBITION "DIVERS ÉGALES UNIS, AN ARTISTIC LOOK AT THE UN UNIVERSAL VALUES" AT THE RATH MUSEUM

On Tuesday 28 September, the CIOMAL Foundation of the Order of Malta had the pleasure to introduce a circle of benefactors and guests to the unique exhibition of the United Nations' art collection "DIVERS EGALES UNIS, An artistic look at the UN universal values." Over 200 works from the United Nations' Collection were exceptionally displayed at the Rath Museum for a few weeks, for the greatest pleasure of the Geneva people. This beautiful exhibition celebrates the values of multilateralism and the Charter of the United Nations.

From left to right: Mr Thierry Zen Ruffinen, chairman of the CIOMAL Foundation - Ms Tatiana Valovaya, Director-General of the United Nations Office at Geneva - Ms Victoria D. Dzodziev, curator of the exhibition "Divers Égales Unis".

In the midst of the works on display, the guests had the opportunity to appreciate a sculpture by the Venetian artist Giorgio Bortoli, "Compassion," which was presented by the Order of Malta to the United Nations in 2011. The participants had the privilege to discuss with Ms Victoria Dzodziev, co-curator of the exhibition. We extend our warmest thanks to her for this incredible experience.

2. BENEFIT EVENING OF THE SWISS-TURKISH ASSOCIATION

Centre: Madame Inci de Boccard, chairwoman of the Swiss-Turkish Association.

To celebrate the 98th anniversary of the founding of the Republic of Turkey, the Swiss-Turkish Association organised its annual ball in the historical salons of the Beau-Rivage Palace in Lausanne. Thierry Zen Ruffinen, chairman of the CIOMAL Foundation, as well as Manfredo Radicati di Primeglio, treasurer, had the honor to attend.

We express our very special thanks to Madame Inci de Boccard, chairwoman of the Swiss-Turkish Association, for inviting the CIOMAL Foundation, which the evening was organised for the benefit of.

3. CIOMAL 2021 CUVÉE

Following the success of its first cuvée in 2020, the CIOMAL Foundation has continued to seek a divine elixir by creating a CIOMAL 2021 Cuvée with Jean-Michel Novelle, creative winemaker and oenologist of the Domaine du Grand Clos in Satigny.

This exclusive box of three delightful Geneva wines illustrates this wonderful quote Louis Pasteur: "Wine is the most healthful and most hygienic of beverages."

4. SOLIDARITY INITIATIVE

A change in the Law on money games has forced us to rethink our idea of a solidarity raffle, which we began in 2020. Instead of our initial project, we have offered a free solidarity initiative open to all. This initiative saw 115 happy winners receive beautiful prizes that were generously donated by local actors supportive of our action, for a total value of over 20,000 francs.

5. 47TH SESSION OF THE UNITED NATIONS HUMAN RIGHTS COUNCIL

Interactive dialogue with the Special Rapporteur on leprosy.

At the 47th session of the Human Rights Council, Mr Hervé Arot, member of the Management Committee, delivered a noteworthy statement proposing the establishment at the national level of joint organisations for persons affected by leprosy and their families in charge of ensuring their economic inclusion through micro-credit, adequate housing, and scholarships.

These national bodies would have a tripartite management: public sector, private sector, and organisations defending the rights of patients and their families. The CIOMAL Foundation believes that a pooling of resources would allow for a much stronger impact. The Special Rapporteur on Leprosy, Ms Alice Cruz, expressed her support to this initiative during the interactive dialogue.

ACKNOWLEDGMENTS

WE COULD NOT DO IT WITHOUT YOU. YOUR DAILY SUPPORT IS INDISPENSABLE TO US !

We would like to hereby thank all our donors, both private and institutional, without whose support none of our activities would be possible.

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