

# ACTIVITY REPORT

# 2018



ORDER OF MALTA  
SWITZERLAND

CIOMAL FOUNDATION



# A FEW WORDS FROM THE CHAIRMAN

In the last few decades, leprosy has been greatly reduced to the extent that the WHO no longer considers it a public health issue. But even though it can now be cured, the disease has not been eradicated. It still affects over 3 million people (both sick or suffering the incapacitating effects of the disease) and is especially prevalent in the poorest regions of the world. Over 210,000 new cases are detected every year, 5% of whom are children under 15. Because of the marks it leaves on the skin, leprosy also results in social exclusion, particularly in schools, workplaces and healthcare centres.

The CIOMAL Foundation has been a central figure in this fight for over 60 years. It works on several issues: prevention and awareness-raising, early detection, medical and surgical treatment, socio-economic rehabilitation, local capacity-building. In 2018, the CIOMAL Foundation was granted special consultative status with the United Nations Economic and Social Council (ECOSOC). The standing gives the Foundation the ability to participate in the work of the Council and its bodies, to consult member States and the United Nations system at large, and to carry out advocacy work at the international level, including on behalf of the persons affected by leprosy and their relatives. Moreover, the CIOMAL Foundation has become a member of the Global Partnership for Zero Leprosy.

In Cambodia, CIOMAL supported the creation in 2018 of the first local association of persons affected by leprosy so that their voices may be heard at the national as well as international levels. In addition, CIOMAL's hospital opened a brand new cutting-edge orthopedic service. Finally, the patients received the pleasant visit of Miss Cambodia and her runners-up, who thus demonstrated their beauty inside and out. They also spent time with the ostracised women and provided them with makeup tips.

In 2018, the Kien Khleang centre accepted 6,322 people (including 1,418 children) for free consultations. Of these, 753 persons had a form of leprosy. 191 were admitted as inpatients, including 169 for surgical procedures. The rehabilitation programmes established by CIOMAL helped 39 families receive microcredit, 32 school children and 7 students receive scholarships. In addition, awareness campaigns reached 56,610 workers in 12 garment factories. As planned, CIOMAL intensified its early detection activities throughout Cambodia, in partnership with the National Leprosy Elimination Program. It also decided to expand its campaigns to the north of Cambodia. A pilot mission is scheduled in 2019 in the province of Ratanakiri, which is inhabited by indigenous minorities who do not speak Khmer. In these remote underdeveloped areas, we know that the work to raise awareness will be crucial to fight the prejudice and customs that are prone to stigmatising anyone who looks different and ostracise them.

CIOMAL's current efforts must be maintained so that leprosy does not regain any ground. In accordance with its mission to fight leprosy and any related forms of exclusion or discrimination, the CIOMAL Foundation seeks to treat and cure the persons affected, and then reintegrate the convalescents by offering them medical and socio-economic rehabilitation. The impact of these ambitious objectives is contingent on the financial support that our private and institutional donors renewed once again in 2018. In the name of those we were able to help, the Foundation Board expresses its utmost gratitude to CIOMAL's loyal and generous donors.

**Thierry Zen Ruffinen**  
Chairman



# CIOMAL'S OBJECTIVES

## **Fighting leprosy and all related forms of exclusion and disabilities around the world.**

**F**or centuries, the Order of Malta has been faced with leprosy and its medical and socio-economic consequences and never stopped fighting the stigmatising disease. To contribute successfully to its elimination, the Order created CIOMAL in 1958, which became a Swiss not-for-profit foundation in 1999 and took the name of 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;**
- **rehabilitating the persons affected.**

Concretely, this means medical and surgical procedures, organising campaigns of prevention, awareness and early detection, trainings for healthcare staff, and finally, financial support for the social and economic rehabilitation of those affected.

### **Foundation Board as of 31st December 2018:**

<b>Chairman:</b>	Mr. Thierry Zen Ruffinen
<b>Treasurer:</b>	Mr. Simon von Oppenheim
<b>Members:</b>	Pr. Philippe Jaeger Dr. Henri Perroud Ms. H�el�ene Genillard Mr. Raymond Loretan
<b>Management Committee:</b>	Mr. Thierry Zen Ruffinen Mr. Simon von Oppenheim Mr. Gilles de Weck Mr. Herv�e Arot
<b>Operational Manager for Cambodia:</b>	Ms. Carole Vann
<b>Development Officer:</b>	Ms. Lauren Bouvier



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From left to right: Mr. Raymond Loretan, member – Pr. Philippe Jaeger, member – Mr. Thierry Zen Ruffinen, chairman  
Ms. H el ene Genillard, member – Dr. Henri Perroud, member – Mr. Simon von Oppenheim, treasurer.



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## A FEW WORDS ON LEPROSY

**L**eprosy (or Hansen's disease) is a chronic infectious disease caused by *Mycobacterium Leprae*, which affects the peripheral nervous system, the skin and mucous membranes and causes severe disabilities. The leprosy bacillus is transmitted via droplets from the nose or mouth, during contacts with an infected untreated subject. The incubation period is about 5 years but symptoms may appear only after 20 years, which makes it difficult to identify those affected.

There is a link between the disease and the level of development of a country. Several factors are relevant: poverty, lack of hygiene, poor nutrition. A healthy person with an efficient immune system will eliminate the bacillus from his or her body.

There are about 216,000 new cases of leprosy every year, mainly in Southeast Asia, Africa and South America. If left untreated, it can cause permanent lesions on the skin, peripheral nerves, eyes and limbs. It can also sometimes result in blindness or a complete loss of sensation in the feet or hands.

Treatment lasts from 6 to 18 months depending on the severity of the case. It is distributed free of charge by the World Health Organization and combines three antibiotics (polychemotherapy).

Unfortunately, the disease is often diagnosed after the patient has already suffered its first consequences. Reconstructive surgery is therefore often required. But in spite of this, fears of ostracism remain a reality.

**There is a link between the disease and the level of development of a country. Several factors are relevant: poverty, lack of hygiene, poor nutrition.**

**Dr. Henri Perroud**  
Dermatologist  
Member of the Foundation board

## RECAP OF CIOMAL'S ACTION IN CAMBODIA IN 2018

**T**he CIOMAL Foundation has been fighting leprosy in Cambodia for 25 years. In partnership with the National Leprosy Elimination Program (NLEP) established by the Cambodian Ministries of Health and Social Affairs, CIOMAL created a rehabilitation centre for leprosy patients in Phnom Penh in 2000. In time, the Kien Khleang centre has become a centre of excellence for the treatment of and training on leprosy in the country. The projects that are developed at the center and on the field cover all aspects of the fight against leprosy: information dissemination, active and early detection of the disease, prevention, medical and socio-economic rehabilitation, and training.



*From left to right: Mr. Gilles de Weck, member of the management Committee – Ms. Lauren Bouvier, development officer – Mr. Simon von Oppenheim, treasurer – Mr. Alexandre Zanetta, fundraising and communication Commission – Ms. Carole Vann, operational manager for Cambodia – Mr. Hervé Arot, member of the management Committee – Mr. Thierry Zen Ruffinen, chairman*

CIOMAL's programmes benefit persons affected by leprosy and their relatives, most of whom have been treated but continue to suffer serious incapacitating consequences. These individuals come from a disadvantaged background and have limited and inadequate access to healthcare. Because leprosy remains feared by all, those affected often face discrimination and exclusion.

Leprosy can be medically cured thanks to poly-chemotherapy, which is provided free of charge by the World Health Organization. It is distributed by the Cambodian Ministry of Health but often-times, the patients do not receive follow-up care from the doctors in Cambodian hospitals, who do not know the disease or are afraid of it. Local healthcare centres are very poorly trained to treat the disease and the national programmes lack resources to implement an effective strategy. CIOMAL is involved in the training of Cambodian medical staff so that over time, the programmes may be integrated into healthcare services.

So, CIOMAL develops its projects in partnership with the local authorities, healthcare personnel and community, as well as with partners working in similar fields. The intervention must be lasting, efficient and integrated to its environment so that the projects may eventually be taken over locally. Training has a crucial role, as does prevention through early detection, information and awareness-raising.

In 2018, in addition to continuing already existing programmes, CIOMAL supported the creation by persons affected by leprosy of their own association, the first of its kind in the history of Cambodia. This will help them advocate for themselves at the national and international levels, as well as facilitate their integration into national rehabilitation programmes, in particular within the Disability Action Council (DAC). Cambodia ratified the UN Convention on the Rights of Persons with Disabilities in 2012.

**Carole Vann**

Operational manager for Cambodia

# CORNERSTONES OF THE CIOMAL FOUNDATION'S WORK

**1. Detecting** those affected as early as possible.

If detected at the first stage of the disease, a person can be treated and cured without any physical signs. As soon as they start receiving treatment, a person stops being contagious.

**2. Providing free treatment** for the persons admitted to the Kien Khleang Center.

**3. Rehabilitating disabled patients** at the medical, surgical, orthopedic and ophthalmologic levels.

**4. Rehabilitating patients at the socio-economic level:** trainings, loans, homes to help them achieve autonomy and social integration.

**5. Training medical and paramedical staff** (knowledge transfer).

**6. Carrying out information campaigns** for patients, authorities and the general public.

**7. Facilitating the integration of those affected by leprosy** into the Cambodian sanitation services.

## KIEN KHLEANG, MEDICAL HEALTHCARE CENTRE

**A**t the heart of CIOMAL's presence, the Kien Khleang Leprosy Rehabilitation Center (KKLRC) has become recognized as the centre of excellence on leprosy in the whole country. In addition to the free treatment for people affected by leprosy and its related complications, KKLRC offers physiotherapy, dermatology and reconstructive surgery services. The center has an operating room, treatment rooms, a pharmacy and a small laboratory. KKLRC has a capacity of 37 beds but can accommodate up to 47 patients if necessary.

In 2018, 5,569 people received free dermatology consultations and 753 patients came for leprosy consultations. Out of these, 42 new leprosy cases (including 5 children) were detected. Of these 42 new cases, 18 had disabilities due to late detection. In total, 6,322 people (including 1,418 children) from disadvantaged backgrounds came from all provinces and received treatment at the centre. Among them, 191 persons affected by leprosy were hospitalized for treatment at KKLRC. 169 of the inpatients underwent surgical procedures that were minor (bone trimming, scraping) or major (hand, feet or eye surgery, such as tendon transfers, rhinoplasty or amputations).



Left:  
Kien Khleang, Medical  
Healthcare Centre  
Right:  
Surgery operation

207 persons underwent physiotherapy. 191 persons received rehabilitation equipment: sunglasses, protective gloves, splints, crutches, adapted and protective shoes, etc.

86 pairs of orthopedic shoes were made for patients with leprosy.

The monthly bed occupancy rate was 49% and the average length of stay was 42 days.

## CLINICAL TRAINING AND PATIENT EDUCATION

In collaboration with the University of Health Sciences of Cambodia, trainings on clinical techniques and practical activities related to leprosy were integrated into the university curriculum. This means that all fifth-year medical and physiotherapy students must attend the leprosy training for at least 20 days, prosthetic and orthotic students for 3 days, and dermatology specialists for 2 months.

In 2018, 68 medical and dermatology students, 41 prosthetic and orthotic students, 16 physiotherapists from provincial centres completed training courses at KKLRC.

The centre's patients have access to recreational and educational activities that help them learn how to live with their disabilities in a sanitary and healthy way. They must learn how to cook or garden without burning themselves or getting injured in limbs that have lost all sensation.

They can also learn how to read and write or have computer lessons. Once a month, they go on group outings into town to overcome inhibitions related to their disabilities.

More recreational activities include karaoke, theater or board games. Every year, KKLRC patients also join various social events organised by the government, such as the International Day of Persons with Disabilities and other events for disabled people.



Left:  
Training  
Right:  
Cooking lessons



## THE EARLY DETECTION OF NEW CASES

**W**ith regard to the detection of new cases, it is important to distinguish between active and passive detection. Until 2011, the CIOMAL Foundation implemented a policy of passive detection (information campaigns, staff training, admission and treatment of patients at the centre) and sought to integrate its programmes into the national health service. But the Ministry of Health did not have a sufficient budget to fight the disease. Moreover, the national healthcare personnel is not sufficiently trained.

Active detection is distinguished by a search for new leprosy cases. In its routine activities, the NLEP is in charge of carrying out such monitoring, detecting new cases and taking a census of those affected. Only national supervisors may provide a diagnosis but as they are underpaid, they lack motivation to do their work as well as skills. This resulted in the detection of 300 to 400 new cases on average every year. But the number has decreased to 249 since 2019. This is a negative balance since it reveals that national supervisors are not carrying out their mission reliably, partly because of the lack of resources and training.



*Early detection of the disease campaign*

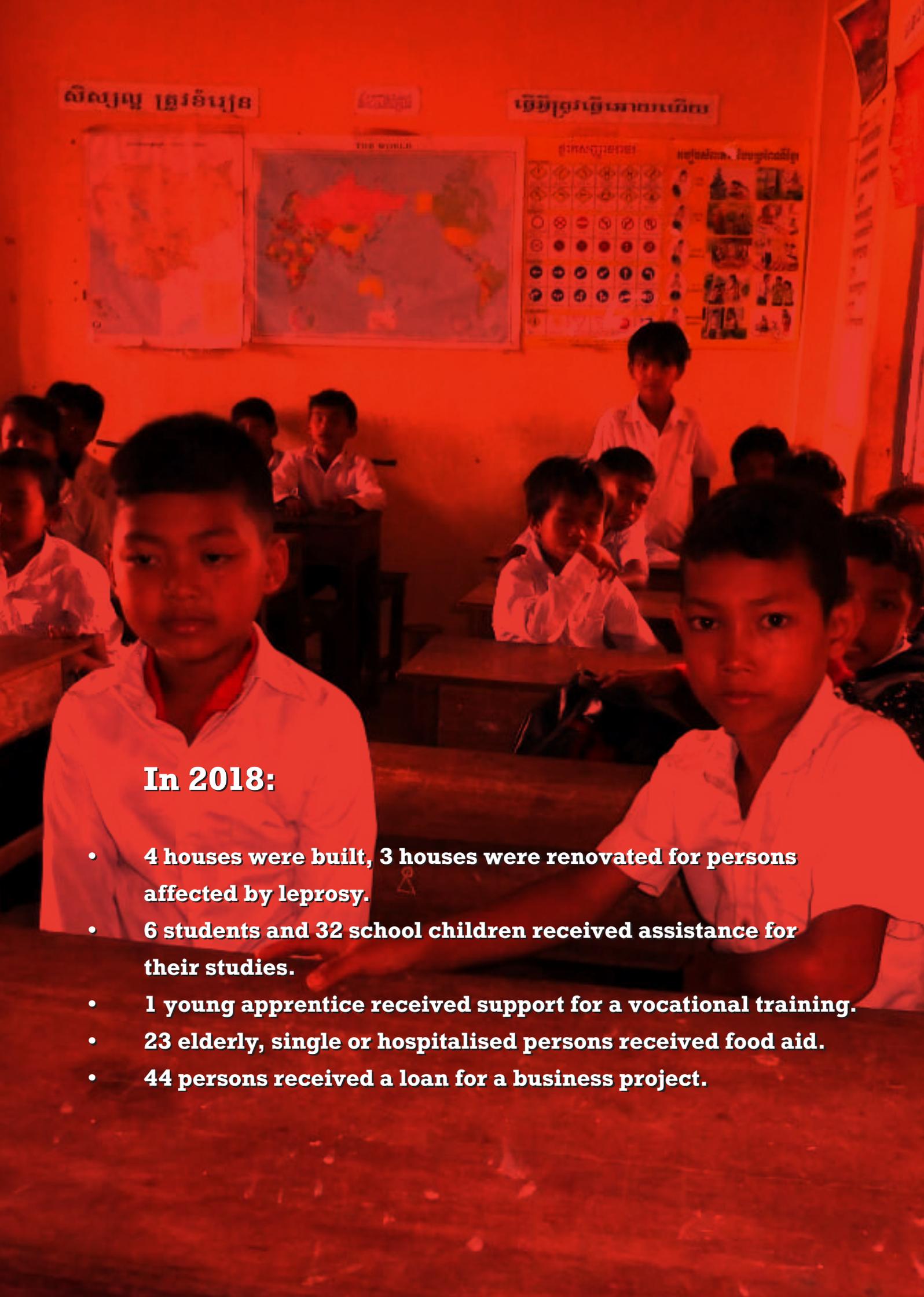
In 2011, with the support of the Novartis Foundation, Netherland Leprosy Relief, the Raoul Follereau Foundation and the Order of Malta France, the CIOMAL Foundation launched Contact Tracing, a pilot project on the early detection of the disease which consists in the active detection of newly declared cases of leprosy. To this end, together with NLEP, a CIOMAL team visits former patients in order to detect new cases of leprosy among their neighbours and relatives and treat them as quickly as possible to avoid serious consequences for them and any propagation of the bacillus to healthy persons. These campaigns started in the districts with the highest rate of people affected by leprosy. The first cycle ended in June 2015. In 5 years, more than 600 new cases were identified through Contact Tracing and received treatment. The data collected during this first cycle was used to determine the scope of work of Cycle 2 and provided reliable statistics on the situation of leprosy in the country.

The second cycle of detection of retrospective active cases/contact tracing started at the end of 2017 and continued in 2018.

Five campaigns were carried out in the provinces of Kampong Thom, Kampong Chhnang, Kampot and Kampong Cham.

In total, these 5 campaigns in 2018 resulted in the detection of 51 new cases of leprosy, including 6 children under 15.

In partnership with the NLEP, the CIOMAL teams have examined 3,743 relatives, 268 former leprosy patients and 470 of their relatives.



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**In 2018:**

- **4 houses were built, 3 houses were renovated for persons affected by leprosy.**
- **6 students and 32 school children received assistance for their studies.**
- **1 young apprentice received support for a vocational training.**
- **23 elderly, single or hospitalised persons received food aid.**
- **44 persons received a loan for a business project.**

## SOCIO-ECONOMIC REHABILITATION

In general, the persons affected by leprosy are vulnerable and very disadvantaged. CIOMAL seeks to provide them with lasting assistance. Our support methodology was developed so that the project may become partly autonomous, limit a number of risks and provide optimum supervision. CIOMAL offers various means of support, including scholarships, food aid for elderly or single people, house building or renovation, or loans for a business project.

To receive support, the beneficiary must fill out a request form, which will be evaluated. The team then visits the person to determine his or her standard of living and eligibility. Then, the file is submitted to an internal committee which rules on the request. A contract is then signed with the beneficiary. Priority is given to the most impoverished persons that meet all conditions. A mandatory training is organised before a loan is allocated. Loans are either USD 150 over 1 year or USD 300 over 2 years, depending on the scope and duration of the business activity submitted by the future beneficiary: raising pigs, chicken or cows, small business, farming. The beneficiaries are informed that the reimbursement of their loan will allow another person to benefit from CIOMAL's aid.



*House renovation before*



*House renovation after*

The scholarships are partly supported by the Peter Donders Foundation and are allocated to the youngest that are affected by leprosy or live with a relative who has the disease. CIOMAL seeks to support the students until they graduate. A team visits the beneficiaries regularly and remains in contact with their families and teachers. Scholarships are awarded for school materials, accommodation and food.



## **AWARENESS CAMPAIGNS**

**Awareness-raising activities help people learn how to recognise the first signs and symptoms of leprosy so they may receive treatment as soon as possible and thereby reduce the disabilities caused by leprosy.**

# AWARENESS CAMPAIGNS



Miss Cambodia

**A**wareness campaigns on leprosy contribute to the elimination of leprosy and its consequences in Cambodia but also to putting an end to the stigmatisation of those affected by leprosy and their relatives. They are carried out by disseminating knowledge on leprosy in rural and urban areas.

In 2018, our awareness action took various forms: awareness campaigns in garment factories, banners fixed on tuktuks and houses, theater shows broadcast on TV, information messages on leprosy broadcast on the radio, an Internet website and a Facebook page in Khmer, and the organisation of various events.



Left:  
World Leprosy Day  
Center:  
Awareness  
Right:  
Orthopedic shoes

## Awareness campaigns in garment factories

**A**wareness-raising events were carried out in 6 garment factories in the weeks leading to the Khmer New Year in April 2018, as well as in 6 other factories before the Pchum Ben holiday in October 2018. 56,610 workers participated to these campaigns. Leaflets and posters that described the signs and symptoms of leprosy were distributed in each of these 12 factories.

During these activities, the CIOMAL team accompanied staff from the Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY) as well as staff from the Ministry of Health (MoH)/NLEP.



*Awareness campaigns in garment factory*

## Raising awareness on leprosy through banners, t-shirts and posters

**I**n 2018, 360 banners on leprosy were displayed on houses in order to raise awareness on the first signs and symptoms of leprosy and to fight discrimination in their communities.

Also, 1,010 t-shirts displaying basic information on leprosy signs were distributed in 12 targeted provinces.

In addition, the CIOMAL teams displayed 171 posters on tuktuks in the same provinces in order to consolidate information on leprosy in rural areas.

Pekmi is a sketch comedy group that performs in a traditional Khmer style. They are very famous and popular in Cambodia. The group prepared a 30-minute comedy show on leprosy and its stigmatisation, which was broadcast 8 times on various TV stations in 2018.

In 2018, CIOMAL signed an agreement with Voice of Persons with Disabilities (VPD) in order to broadcast information messages on leprosy on the radio in 18 provinces. The messages were broadcast twice a day at 12pm and 4pm.



*Information campaign on touktouks*

## World Leprosy Day

**C** IOMAL celebrated World Leprosy Day in January 2018. In Phnom Penh, an open day was organised at KKLRC on 24 January to present CIOMAL's activities as well as information on leprosy. The event was attended by 75 representatives of various national and international organisations, students from various universities, and about 60 former leprosy patients (including 31 who were former inpatients at KKLRC).



World Leprosy Day

## Miss Cambodia Event

**I**n July 2018, 4 Miss Cambodia 2017 paid a visit to KKLRC. They chatted with patients and gave make-up advice to women affected by leprosy. The event aimed at raising awareness with the general public but it also offered the opportunity for the patients, the CIOMAL team and the audience to meet the Khmer beauty queens and discuss leprosy. More than 100 people and 5 journalists were in attendance.



Miss Cambodia: make-up workshop for patients with leprosy

## Creation of an Internet website, a Facebook page in Khmer and the Association of Persons Affected by Leprosy

The first Congress of Persons with Disabilities Affected by Leprosy took place on 31st May 2018 as part of the creation of the Association of Persons with Disabilities Affected by Leprosy. The congress was held in Traeung Village, in the province of Kampong Cham, with the support of the Disability Action Council (DAC) and the Ministry of Social Affairs. Members of the board of directors and the executive committee were elected during the congress.

Eminent personalities attended the congress, including H.E. Ung Sambath (DAC, MoSVY), H.E. Em Chan Makara (DAC, MoSVY) and Dr. Lay Sambath (NLEP, MoH).

In total, 105 people took part in the event, as well as journalists from various media such as the Cambodian National Television, CNC TV and Fresh News.



Association of People with Leprosy

## Workshop on orthopedic shoes and sandals

In January 2018, KKLRC opened a workshop to make orthopedic shoes and sandals, mainly for disabled persons affected by leprosy in Cambodia. The orthopedic shoe technologist has been trained at the Vietcot Training Center for Orthopedic Technologists in Hanoi, Vietnam.

The goal of the orthopedic shoe and sandal workshop is to provide quality orthopedic shoes and sandals to those affected by leprosy in order to prevent further foot deformity, to protect foot ulcer, and to correct the foot that has serious deformations. The orthopedic shoes and sandals are made specially for different types of foot problems, such as post-polio, club foot, pes planus, pes calcaneus, hallux valgus, pes cavus, pump bump, plantar fasciitis, limb length discrepancy, drop foot, amputated foot, diabetic foot. Types of shoes that can be made in the workshop are the following: instep shoes, Oxford shoes, Derby shoes, temporary shoes, boots and sandals.



Orthopedic shoes

## Other activities

In 2018, 157 people visited KKLRC to learn more about leprosy in Cambodia and CIOMAL's activities. The visitors included 60 German dermatologists who had attended the dermatology conference organised in Cambodia by the University of Health Sciences.

In addition, Memorandums of Understanding were signed between CIOMAL and the prosthetics and orthotics department as well as the Ministry of Social Affairs.



Other activities



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ជនពិការភ័យជា  
២ ជនពិការអន្តរជាតិ

## RECOGNITIONS

We would like to thank all our donors, private and institutional, without whose support we could not carry out these activities for those affected by leprosy and their relatives.

### **Special thanks to :**

The Swiss Association of the Order of Malta;  
The Order of Malta France;  
The Monaco Association of the Order of Malta;  
The City of Geneva;  
The Canton of Geneva;  
the Peter Donders Foundation;  
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the ANESVAD Foundation;  
the Raoul Follereau Foundation.

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**ORDER OF MALTA**  
**SWITZERLAND**  
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**CIOMAL Foundation of the Order of Malta**

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