WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE Elimination OF Leprosy

February 2009 • Number 36

- **Leprosy is curable**
- **Free treatment is available**
- **Social discrimination has no place**

Religious leaders join Yohei Sasakawa, flanked by Farida and Kofi Nyarko, at the Global Appeal 2009 launch in London on January 26.

MESSAGE

Faith Leaders Speak Out

Timed to coincide with World Leprosy Day the previous day, the launch ceremony for Global Appeal 2009 to End Stigma and Discrimination against People Affected by Leprosy was held on January 26 at Church House adjacent to Westminster Abbey in London.

The purpose of this appeal is to spread correct understanding of leprosy and banish the social stigma and discrimination that people affected by the disease and even their families face. Since 2006, when I launched the first appeal, I have enlisted the support of different individuals and groups in this effort, and I reiterate my thanks to them all.

For this, the fourth Global Appeal, 17 religious leaders representing Christianity, Islam, Judaism, Buddhism, Hinduism and other faiths joined me in putting their names to this initiative. Before the appeal was read out by Kofi Nyarko of Ghana and Farida from Indonesia on behalf of people affected by leprosy everywhere, representatives of the signatories gathered on stage to convey messages of support. Joining hands, they pledged to rid the world of the stigma associated with leprosy and the discrimination it breeds.

In order to correct the mistaken impression that many people have of leprosy and to ensure that there is a common understanding of this disease, religions can play a vital role. Therefore, I was delighted to hear these religious leaders dispel the notion that leprosy is a "curse" or "God's punishment" and commit themselves to helping secure respect for the human rights of people affected by leprosy and their families.

I hope and believe that this message will reach their tens of millions of followers around the globe, and, through them, spread throughout society at large. Only when all of us are aware and involved can we hope for an end to leprosy and the discrimination that people affected by the disease have endured through the ages. In the words of Global Appeal 2009, "Let the healing begin today."

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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Global Appeal Returns to UK

Religious leaders express solidarity with people affected by leprosy.

AUTHOR:
Dr. David Tharp

British religious leaders representing the major world faiths met in London on January 26 to voice strong international support for the Global Appeal 2009 initiative, which calls for the recognition of the human rights of persons affected by leprosy. Specifically, the inter-faith gathering emphasized the need to eliminate social discrimination associated with the disease.

The launch of the fourth Global Appeal to End Stigma and Discrimination against People Affected by Leprosy was held at Church House, adjacent to Westminster Abbey. The event was timed to coincide with World Leprosy Day. Christian, Islamic, Hindu, Buddhist and Jewish leaders in the United Kingdom each spoke on behalf of their faiths in support of the Global Appeal initiative. Representing people affected by leprosy were Kofi Nyarko of Ghana and Farida of Indonesia.

The Dean of Westminster, the Very Reverend John Robert Hall, gave a welcoming speech to an audience of over 100, including his religious counterparts, the mass media, and representatives of various NGOs that work worldwide to eliminate leprosy. The walls of the conference room in which the event took place were decorated with dozens of vibrant, colorful paintings produced by men and women affected by leprosy.

‘EXTREMELY DAMAGING TERM’

Yohei Sasakawa, WHO Goodwill Ambassador for the Elimination of Leprosy, gave the keynote address. In it, he appealed for an end to the use of the word “leper,” which he described as “an extremely damaging term.” Pointing out that people affected by leprosy have demanded that the word no longer be used, he added that it “carries the meaning of a pariah, or social outcast. Once that label has been applied, it sticks for the rest of a person’s life. The stigma remains, even after he or she has been cured.”

This year’s Global Appeal, which follows appeals by world leaders (New Delhi, 2006), leaders of people affected by leprosy (Manila, 2007) and human rights NGOs (London, 2008), was signed by 17 religious leaders. They included Archbishop Desmond Tutu, the Dalai Lama, the Chairman of the Indonesian Council of Ulamas, the President of the Japan Buddhist Federation, the Chief Rabbi of Israel, the President of the Pontifical Council for Health Pastoral Care at the Vatican, and the General Secretary of the World Council of Churches.

Time out to admire paintings from the Bindu Art School

Sasakawa said that removing discrimination from society “requires the cooperation of society’s most influential members. Therefore, I ask the religious leaders who have signed this year’s Global Appeal to convey its message to their believers and followers.”

Global Appeal 2009 was truly an inter-faith gathering.

Leaders of the various religious faiths in Britain and others visiting London to attend this Global Appeal conference each then rose to voice their individual organizations’ support for the initiative.

These representatives included Dr Bayan Alaraji, Representative of the Islamic Supreme Council of Iraq; Sheikh Ahmed Babikir, Imam of Islamia Schools of London, on behalf of the Islamic community; His Eminence Archbishop Gregorios of Thyateira and Great Britain; Sanjay Jagatia, Secretary-General, National Council of Hindu Temples UK, representing the Hindu community; Dr Manoj Kurian, Programme Executive, Health and Healing, World Council of Churches; Father Edward J. Lewis, Chaplain to Her Majesty the Queen, on behalf of the European Network of Health Care Chaplaincy; Tsering Tashi, representative of His Holiness the Dalai Lama, the Office of Tibet; and Reverend Mgr Brian Udaigwe, Counsellor of Nunciature, on behalf of the President of the Pontifical Council for Health Pastoral Care at the Vatican.

In summary of the united thoughts and feelings of the conference, Kofi Nyarko and Farida read together the Global Appeal message, which calls for the end to social discrimination against persons affected by leprosy and appeals for the recognition of their basic human rights. “All of us,” they read, “must be part of the social healing process.” ■

‘Honored to Be Part of the Struggle’

Messages of support form central part of Global Appeal 2009 event.

As part of the Global Appeal 2009 launch event, messages of support from religious leaders and groups were read out during the ceremony. Here are some edited excerpts.

Leprosy is just like any other illnesses. It has its causes. Our task is to eliminate the causes of the illness, not to look at it as if it is the curse of God.

— His Eminence K.H. Sahal Mahfud, Chairman,
Indonesian Council of Ulamas

People affected by leprosy must be given physical relief, but providing human warmth and a sense of value are equally important. I pray this Global Appeal will encourage a greater awareness that real care of the sick does not begin with drugs and medication, but with the simple gift of affection and love.

— His Holiness the 14th Dalai Lama

Disease can strike the most powerful as well as the most vulnerable. The challenge to combat all disease — in our particular case, the disease of leprosy — is a challenge for all humanity. Judaism teaches us, on the basis of the Bible, to see healing as a Divine process; and to see people who facilitate healing as Divine emissaries. May this Appeal and all who work for its fulfillment succeed in their Divine mandate to provide healing for the body and the spirit.

— His Eminence Rabbi Yona Metzger,
The Chief Rabbi of Israel

I feel greatly honored to be part of the struggle against one of the world’s oldest and most feared diseases. My endorsing and signing of Global Appeal 2009 is a sign of the Catholic Church’s commitment to the alleviation of human suffering and the promotion of the rights and God-given dignity of every individual.

— Cardinal Javier Lozano Barragan, President,
Pontifical Council for Health Pastoral Care

May this Appeal remind the world that the highest reaches of public health and well-being that societies can achieve are based on the firm foundation that the most vulnerable person in each society has access to dignity, respect, love and wholehearted service.

— Reverend Dr. Samuel Kobia, General Secretary,
World Council of Churches

In January 2002, I was part of a delegation that visited a leprosy colony at Tahirpur on the outskirts of Delhi. I made a point of meeting as many families as possible. One woman I met said to me, “Thank you very much for coming to my home and sharing a cup of tea with us. You are the only ‘normal’ person who has done this.” The fact that she thought of me as being any more normal than her brought a tear to my eyes. She went on to tell me that everyone within the colony was shunned by society and she prayed for the day when her family would be treated normally with respect, honor and dignity. We must all support the aims and objectives of the Global Appeal in order to achieve the goal of bringing people affected by leprosy into mainstream society.

— Sanjay Jagaita, Secretary-General, National
Council of Hindu Temples UK

I welcome the opportunity to remind ourselves of individuals and communities in lands across the globe who live with the scourge of leprosy in the 21st century. In addition to the physical effects of the disease, sufferers also experience social exclusion, vulnerability, and poverty, and the Global Appeal will bring a new focus to their plight.

— The Most Reverend Archbishop of Canterbury,
Dr. Rowan Williams

We have to work hard to help people rejected by society develop a sense of self-esteem. They need to be shown compassion. In Iraq, we promise that we will do more to help people with leprosy go back into society. This will be done by increasing resources to treat patients and educating the community to change their views toward the ones who contracted the disease for no sin they committed.

— Dr. Bayan Alaraji, Representative of
the Islamic Supreme Council of Iraq

It is my sincere hope that those who suffer from leprosy, and from the discrimination caused by society’s lack of understanding of the disease, will be free from their suffering and be able to live contentedly with their families. I believe that religions, which offer spiritual support to people around the world, have an important role to play and the power to make this happen.

— The Most Venerable Yukei Matsunaga,
President, Japan Buddhist Federation

I am delighted to support this Global Appeal. The effect can only be that the human rights of those affected will be respected and strengthened.

— His Eminence Archbishop Gregorios of
Thyateira and Great Britain ■

Getting to Grips with Discrimination

Stakeholders discuss principles and guidelines at OHCHR consultation in Geneva.

The UN Human Rights Council's unanimous adoption last June of Resolution 8/13 on the elimination of discrimination against persons affected by leprosy and their family members was a historic development. Realistically, however, much has to happen if this goal is to be realized.

As a next step, Professor Shigeki Sakamoto, a member of the Human Rights Council Advisory Committee, is now drafting principles and guidelines on ending discrimination, which are to be presented to the Council by September 2009.

To assist him in this task, the Office of the High Commissioner for Human Rights organized a one day open-ended consultation in Geneva on January 15 that brought together representatives of governments, leprosy-related NGOs, people affected by the disease and experts in other fields, including HIV/AIDS. To supplement this official consultation, The Nippon Foundation hosted a second day of informal discussions on January 16 to allow more time for the participants, especially people affected by leprosy, to make their voices heard.

USEFUL TOOL

About 70 people attended the January 15 program, which was split into three sessions: the principle of non-discrimination in international law; health-related discrimination and human rights; and discrimination against persons affected by leprosy and their families. Among the issues raised were what actions can be taken to fight discrimination using existing laws and conventions, and what can be learned from other diseases that attract stigma.

Stefan Tromel (International Disability Alliance) made a strong case for using the new Convention on the Rights of Persons with Disabilities as a tool for achieving the goals of people affected by leprosy. With its broad definition of disability, and its insistence that persons with *all* disabilities have rights and fundamental freedoms, he suggested it covered all the situations raised at the consultation.

In outlining the steps that have been taken to combat stigma in HIV/AIDS, Susan Timberlake (UNAIDS) stressed the importance of the engagement and participation of those living with the disease. "This has been one of the driving forces that have kept states on their toes," she said. "Nothing about us, without us."

Not all participants agreed that the debate on leprosy and human rights should be taking place within the parameters of health-related discrimination. Speaking from the floor, Anwei Law (IDEA) said, "When you look at the history of leprosy, this discrimination goes way beyond health."

This was borne out in the presentations from leprosy-affected persons. They included Valdenora da Cruz Rodriguez (MORHAN) and Leulseged Berhane Asres (ENALAP), who described, respectively, the depth of discrimination people affected by leprosy have endured in Brazil and Ethiopia.

TWIN-TRACK APPROACH

Dr. Wim van Brakel (KIT) suggested a twin-track approach was necessary in combating stigma. There is a lot to be gained from a common approach with people who face discrimination due to other diseases, he said. On the other hand, there are some specific issues with regard to leprosy, related to culture and religion, that require special attention. "We need to give leprosy, and leprosy-affected persons, the focus they are due," he said.

For his part, Professor Sakamoto assured those present that he would keep in mind the distinctiveness of leprosy, and the long history of discrimination, when compiling the guidelines. This is also the position of the Japanese government, which proposed the original HRC resolution.

The next day, Professor Sakamoto received further advice as participants in the informal consultation split into groups and brainstormed on what form the guidelines should take and what they should include. Among the suggestions: although the guidelines relate to leprosy, they should be couched in terms of the universality of rights; they should promote affirmative action; they should call for punitive action against those who discriminate; they should promote opportunities for people affected by leprosy to be included in the decision making; and they should be aimed not just at governments but others, too, especially the media.

Thanking everyone for their input, Professor Sakamoto said: "The principles and guidelines may not satisfy everyone, but your frank comments have made my job easier." ■

VOICES:

We have been disregarded and undermined for generations, even by those whom we call our own relatives and friends, because of the superficial scar of the disease called leprosy.

— Leulseged Berhane,
Chairman, ENALAP

Discrimination in Brazil is largely due to lack of education of the people about leprosy. This ignorance includes patients themselves and medical personnel.

— Valdenora da Cruz
Rodriguez (MORHAN)

Those of us working in leprosy should take very seriously the opportunity to make alliances with other marginalized groups and work together to ensure rights are upheld for everybody.

— Douglas Soutar,
General Secretary, ILEP

This issue should not be linked to a right to health. It goes beyond that. It is a deep-rooted, deep-seated prejudice in the history of mankind that we need to deal with separately from other diseases.

— Minister Akio Isomata,
Permanent Mission of
Japan to UN in Geneva

Pain and Progress

Liu Zhen Xi speaks of the experiences of people affected by leprosy in China.

AUTHOR:

Liu Zhen Xi is vice president of the HANDA Rehabilitation and Welfare Association, an organization of people affected by leprosy in China. He lives in a leprosy resettlement village in Guangzhou Province.

I was diagnosed with leprosy at the age of 13. Soon after, I was forced to drop out of school and enter a leprosy hospital.

After about nine years of treatment, I was discharged. Unable to return home, however, I lived alone in a small hut next to a sugarcane field. I thought I could fend for myself and face up to the stigma, but I couldn't bear the way the discrimination affected even my family and relatives. After learning that my nephew's girlfriend had run away when she found out his uncle had had leprosy, in 1993 I moved to a leprosy village.

Mine is not a special case. Many people affected by leprosy in China have undergone similar experiences. People are still being turned away from public facilities, denied access to public services and prevented from going to school or getting a job.

LEFT TO DIE

In April 2008, Ms. Liang Yuehui, a 70-year-old woman who lived in my village, required emergency medical treatment. We called an ambulance, but when it reached the outskirts of our village, the ambulance crew refused to proceed further after discovering where they had come.

They complained that we hadn't told them we lived in a leprosy village, and said they didn't have the means to isolate the patient. Even though we assured them there were no leprosy patients in the village and that no one was infectious, they wouldn't change their minds and drove off. As a result, Ms. Liang did not receive the treatment she required and died one month later.

Another incident in 2008 also troubled me greatly. When HANDA was organizing a get-together with residents from another village to promote communication and exchange, we planned a dinner at a local restaurant. We booked a table and paid for the reservations.

Liu Zhen Xi (right) with HANDA's Michael Chen in Geneva

But just a few hours before the meal, the restaurant canceled our booking and insisted on returning our money. Even though we explained about leprosy, they refused to serve us. "We can't have leprosy patients eating at our restaurant," they said. "If other people found out, we would soon have to close down."

> "I keep asking myself why we can't live normally like other people."

These are just a couple of incidents that I experienced personally last year, and there are many other examples of stigma and discrimination happening around me.

Mr. Zhong is a skillful welder who was fired by his company when they found out he once had leprosy. Our colleagues in Sichuan Province were turned away by a small hotel in Duiping, Jinyang County, when the staff learned they were from Jinyang leprosy village. The children from Xide leprosy village were not allowed to study at the local public school just because of where they lived.

All these stories pain my heart. I keep asking myself why we can't live normally like other people and enjoy the same treatment and equal rights. But I realize that day will come, only when more attention is paid to our rights and the public has a better understanding of leprosy.

In recent years, the Chinese government has been trying to bring about a harmonious society. It has made a tremendous effort to improve the living conditions of people residing in leprosy villages. There are also some NGOs, volunteer groups and warmhearted individuals in China that are working together to fight against discrimination. More and more people are starting to understand and accept those of us affected by leprosy, and now we are able to participate in the wider community. But as the examples above show, stigma and discrimination still exist.

On behalf of people affected by leprosy everywhere, HANDA appeals to international organizations and groups, and to the governments of all countries, to take up the issue of leprosy-related discrimination and to promote equal rights for everyone, including people affected by leprosy. ■

Footnote

This article is based on a presentation Mr. Liu made at an informal consultation on the elimination of discrimination and stigma against people affected by leprosy and their families in Geneva on January 16, 2009.

Signs of Progress in Nepal

Kathmandu's new government seems committed to the cause of moving beyond the milestone of leprosy elimination.

NEPAL (DECEMBER 3–7)

My trip to Nepal at the end of the year left me with feelings of guarded optimism that it will now come to grips with eliminating leprosy as a public health problem. Nepal is one of the three countries yet to pass this interim goal. It has been through some difficult times in recent years, but the new government seems to be taking things in hand.

During my trip, I met with Minister of Health and Population Dr. Girirajmani Pokharel, one of the few members of the previous Cabinet to have retained his job. The minister told me that "in the new republic, there should be no place for leprosy," and gave his commitment to seeing Nepal achieve elimination in 2009.

His words were echoed by Prime Minister Pushpa Kamal Dahal (Prachanda), with whom I had an audience later the same day. Prachanda told me, "We are trying to build a new Nepal, and we want to build a Nepal without leprosy."

One of the health minister's most positive steps was to appoint Dr. Garib Das Thakur as chief of the Leprosy Control Division of the Department of Health Services. This appointment took effect just two weeks before my arrival. Under Dr. Thakur, the program will be both field-oriented and action-oriented, and I believe he will make an important contribution to the leprosy control program.

The WHO's representative in Nepal, Dr. Alexander Andjaparidze, is working closely with Dr. Thakur and also expressed confidence that the elimination program is getting back on track. He told me that special teams had been formed to conduct a three-month trial in three districts where the leprosy prevalence rate is high. If these trials prove successful, then this approach will be extended to other districts.

Leprosy prevalence rates stand at less than 1 per 10,000 in 49 of Nepal's 75 districts. In the remaining 26 districts, it is higher than 3 per 10,000 in just 3. By region, the PR is above 1 in all five of Nepal's official regions. Two regions, however — the Eastern Development Region (EDR) and the Central Development Region — yield 63% of the nation's new cases. More than 80% are from the low-lying Terai belt bordering India.

> "The prime minister told me, 'We are trying to build a new Nepal…without leprosy.'"

For this reason, visiting districts in the Terai belt was the main purpose of my trip to Nepal this time.

On December 3, I flew to Jhapa District for a briefing by the district public health officer. Next, I attended the opening ceremony of a women's empowerment workshop organized by IDEA Nepal. Some 25 women affected by leprosy took part in the event, the sixth of its kind run by IDEA Nepal. In the afternoon, I called at a leprosy clinic located within a Primary Health Center (PHC) in Gauriganj.

The following morning, I visited Mangalbari PHC, in Morang District. This health center currently has 28 patients under treatment for leprosy. I was able to meet some

With Prime Minister Prachanda in Kathmandu

Volunteer health workers at Mangalbari PHC

VOICE:

We have come a long way, and are at a stage of final effort to eliminate leprosy from Nepal. Let me take this opportunity to thank the thousands of dedicated health and community-level workers for their contribution. In Health and Population Minister Sri Girirajmani Pokharel, Nepal has a committed leader to achieve this goal, and the goal is within our reach.

— Dr. Alexander Anjaparidze, WHO Representative in Nepal (excerpted from his 2009 World Leprosy Day Message)

A courtesy call on Lalgadh Leprosy Services Center

of them, along with some 50 female volunteer health workers serving the local community.

Following that, I was briefed by the Morang District public health officer, and attended street theatre designed to raise leprosy awareness. The specially arranged performance took place in the forecourt of a hospital that included a regional leprosy clinic — my next stop.

Street theater in Dhanusha District

At the hospital, I was given an overview of the situation by EDR Regional Director of Health Dr. Naresh Pratap K.C. Apparently, quite a few patients come from India, and this was borne out when I met a woman from neighboring Bihar who had brought her 10-year-old daughter to Nepal for treatment. However, I understand that while the health authorities treat patients from India, they do not include them in Nepal's case register.

After flying back to Kathmandu, I returned the next day to the Terai, this time to Dhanusha District. The first event on my itinerary was another performance of street theatre. I have seen many such performances in my time, but this was one of the best. Two or three hundred people encircled the actors, who skillfully played out a tale of diagnosis, rejection, understanding and acceptance. I believe activities such as these are a highly effective way of reaching people with information about the disease, and judging from the enthusiastic reaction of the onlookers, they will not soon forget the message that leprosy is a curable disease.

After a brief stop at Dhalkebar Health Post, I proceeded to Lalgadh Leprosy Services Center, built and run by the Nepal Leprosy Trust. Time constraints kept my visit short, but it was enough for me to form a very favorable impression of a well-run facility staffed by a dedicated and caring team.

The center is situated in neat, campus-like surroundings, and is composed of several different buildings. It has 52 beds and serves as a referral hospital for the surrounding four districts, handling leprosy reaction and other difficult cases. In addition to providing medical services, it also trains government health workers and volunteers, supports self-care groups and conducts awareness campaigns among the general population. Indeed, the Center was responsible for organizing the street drama that I so enjoyed earlier in the day.

During this trip to Nepal, I was very impressed by a suggestion that the WHO's Dr. Andjaparidze made to the health minister for breaking down stigma. He suggested that patients who have been cured of leprosy should receive a 'treatment completed' certificate bearing the minister's signature. I thought this was an excellent idea, and I will be interested to see what comes of it. ■

Countries Mark World Leprosy Day

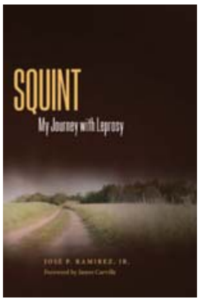
Opportunity to raise awareness and promote human rights

PerMaTa rallies in Jakarta on World Leprosy Day.

Around the world, people affected by leprosy and groups working to eliminate the disease staged rallies on January 25 to mark World Leprosy Day. In Indonesia, PerMaTa organized events in several locations, including this march (seen at left) in the capital, Jakarta.

In India, where the day is celebrated on January 30, the anniversary of Mahatma Gandhi's assassination, representatives of the National Forum, an organization of people affected by leprosy headed by Dr. P.K. Gopal, met with the country's president, Smt. Pratibha Devisingh Patil.

Held on the last Sunday in January, World Leprosy Day was started by Raoul Follereau in 1954. "Shall we leave millions of human beings to rot and die when we can, truly, treat them and probably cure them?" he wrote in announcing his initiative. "Why them and not me?"



SQUINT: MY JOURNEY WITH LEPROSY

Jose Ramirez, Jr., has authored a compelling account of his battle with leprosy, the associated stigma, and his role as an advocate for people affected by the disease.

Published by the University of Mississippi Press on February 1, 2009, Ramirez' story includes the nearly 10 years he spent at a leprosarium in Carville, Louisiana, and details the unconditional support he received from family and loved ones. For more information: http://leprosyjourney.com ■

FROM THE EDITORS

A 21ST CENTURY 'MIRACLE'

Last spring, there was a ground-breaking political event that rivaled the recent swearing-in of Barack Obama as the first black president of the United States. Unfortunately, however, it was one that went largely unnoticed by the world.

On May 30, 2008, Lim Doo-Sung became the first person affected by leprosy to be elected to South Korea's National Assembly — according to Mr. Lim, he is the first person affected by leprosy anywhere to be elected to a national parliament.

During a visit to Geneva last month for an open-ended consultation on ending discrimination against people affected by leprosy, Mr. Lim described his election as the most surprising and encouraging news of the 21st century, given the social discrimination and the prejudice countless generations of people with Hansen's disease have had to endure. "History has been cruel to Hansen's-disease patients," he said. "It has made them suffer unnecessary pain over and over again, from forced segregation and sterilization to abortion and experimentation. They have been treated as patients even after being cured, and have lacked human dignity for a long, long time."

As one who has personally experienced the pain and hurt of stigma and discrimination, Mr. Lim said his electoral success was nothing short of a miracle, and should serve as an inspiration to minorities everywhere. "A miracle happened in 2008. I think this instant is equal to, or even more dramatic, than the election of a black president of the United States."

As an assemblyman, Mr. Lim said, he wants to be a source of hope to people affected by leprosy in South Korea and around the world, to show the potential and energy of people affected by Hansen's disease and "to end this dark period of history."

As he finished speaking, Mr. Lim drew a burst of applause from those listening. It was a show of support for the man and his mission. We wish him well.

FOR THE ELIMINATION OF LEPROSY
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