WHO GOODWILL AMBASSADOR'S

# LEPROSY BULLETIN

NO. 106 NOVEMBER 2021

## Building back better to realize a leprosy-free world

### Message from the ambassador

According to the World Health Organization's annual global leprosy update, there were 127,396 new cases detected in 2020, a 37.1% decrease in comparison to the previous year. In my view, this is not good news. Because of the COVID-19 pandemic, many countries stopped or postponed their leprosy control activities, including active case-finding. A reduction in active case-finding naturally results in fewer cases being detected.

As the WHO Goodwill Ambassador for Leprosy Elimination, I have visited more than 120 countries and spoken directly with presidents and prime ministers about the importance of leprosy control. I believe that changing the thinking of national leaders is a shortcut toward improved control. Since I started my efforts, many countries have reached elimination of leprosy as a public health problem, but there is more to be done.

I believe that leprosy is a disease like no other. Medical treatment cures the disease, but because of social discrimination, persons affected by leprosy feel that they have not recovered. Considering that generation after generation all over the world this discrimination has continued, we should think of the elimination of leprosy as one of humanity's most deeply held desires.

I launched the "Don't forget leprosy" campaign on the occasion of my 20th anniversary as the goodwill ambassador because I want us to remember that we still have work to do. I am calling on organizations of persons affected by leprosy, NGOs, governments, and other stakeholders around the world to join this campaign. I sincerely hope that we can share the same vision and fight together against leprosy.

笹川陽平

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

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**LEPROSY IS CURABLE. MEDICATION IS FREE. STOP DISCRIMINATION NOW.**

VIEWPOINT

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**President, International Leprosy Association**
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# Essential elements of post-pandemic leprosy services

From the latest *Weekly epidemiological record* on leprosy (Hansen's disease) published by the World Health Organization (WHO), the impact of the COVID-19 pandemic on the fight against leprosy has been clearly highlighted. Indeed, WHO reports a reduction of 27.7% in the recorded prevalence and of 37.1% in the number of new cases compared to 2019. These reductions are probably attributable to consequences of the COVID-19 pandemic.[1]

Most of the countries where leprosy is endemic have been confronted, like other countries in the world, with the COVID-19 pandemic. However, their largely underfunded health systems are unable to cope with the pressures induced by the management of this pandemic. Containment and social distancing measures are difficult for the most vulnerable, including leprosy patients. For them, accepting confinement often condemns them to finding nothing to eat. Hygiene measures are very difficult to comply with due to poor access to water and soap. The economic consequences induced by the pandemic penalize in the very short term the demand for care, the education of children, and the financing by the government of vital sectors such as education and health.

One of the important principles that should guide the organization of post-pandemic leprosy services should be the involvement and full participation of persons affected by leprosy at all levels of the organization of the services dedicated to them. These services must include the following essential elements.

## Access to early detection and diagnosis

Early detection must take place in strict compliance with barrier measures against COVID-19. Health authorities as well as all stakeholders in endemic countries should provide necessary information to persons affected by leprosy and their families for this purpose. Awareness campaigns should be dedicated to the precautions to be taken to ensure early and safe screening for patients and their families.

## Patient care and case management

The provision of treatment, in particular MDT, must be ensured for all patients diagnosed. This is of utmost importance. Sufficient stocks of drugs must be anticipated and made available. New technologies should be used to monitor treatments. Care should be taken to provide the patient with the necessary information and medication to prevent and anticipate complications that may arise during and after treatment. Basic hygiene, sanitation, and water services should also be made available to patients and their families in order to ensure safe care in this post-pandemic period.

## Services for persons living with a disability and/or psychosocial consequences of leprosy

Persons affected by leprosy, especially those with disabilities, may face stigma leading to social exclusion and mental disorders such as depression and anxiety. Persons affected by leprosy can be helped by socio-economic rehabilitation services and self-care groups. However, the main COVID-19 control measures such as social distancing and self-isolation directly interfere with these services. Post-pandemic leprosy services should therefore pay particular attention to these problems by providing appropriate care as well as the information and services necessary for patients and their families.

## Access to vaccination and prevention services

Vaccination and prevention services for COVID-19 must now be part of the services offered to patients with leprosy, and this with strict respect for their dignity. Sufficient information should be provided to them in order to have their own participation in decisions concerning their health. Care should be taken to avoid discrimination in access to prevention services for patients and their families. Health personnel should be trained in this regard to provide patients with useful information and appropriate care for this purpose.

Governments and all stakeholders should ensure that the basic services mentioned above are provided to patients with a view to reducing the negative effects of this pandemic on leprosy control.

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[1] World Health Organization, "Global leprosy (Hansen disease) update, 2020: impact of COVID-19 on global leprosy control," *Weekly epidemiological record* 96, no. 36 (Sept. 10, 2021): 421-444, https://www.who.int/publications/i/item/who-wer9636-421-444.

DATA BOX

# WHO’s global leprosy update (2020 data)

Every year, the World Health Organization (WHO) receives official data on leprosy from national programs in member states worldwide. For the calendar year 2020, WHO received data from 127 countries, including all 23 global priority countries. WHO released a report on this data in September 2021.[1]

## Interpret data indicating reduction in 2020 with caution

In 2020, health services everywhere experienced extra burdens and disruptions because of the COVID-19 pandemic. WHO’s report states that lower numbers (see table at right) reflect operational factors rather than an underlying epidemiological shift and warns that the interruption in case detection related to such operational factors as reassignment of staff and cessation of community-based activities may result in hidden cases and an increase in grade 2 disabilities (G2D). The data should be interpreted with caution, especially when calculating long-term trends.

**Selected comparison of 2019 and 2020 world data**

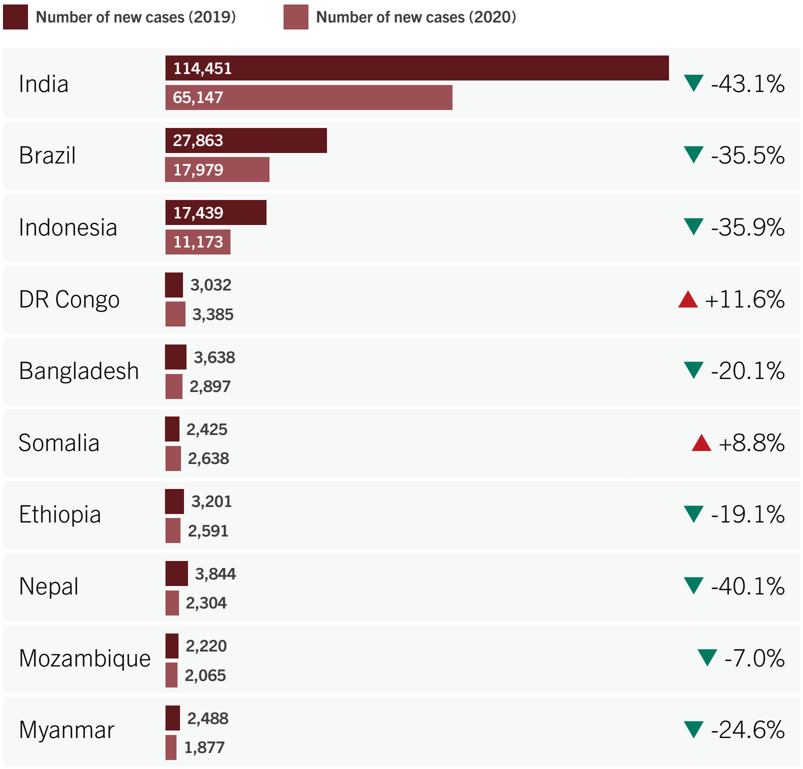
| World data | 2019 | 2020 | Percentage change |
|---|---|---|---|
| Number of registered cases at the end of the year | 178,371 | 129,192 | ▼ -27.6% |
| Number of new cases detected | 202,488 | 127,396 | ▼ -37.1% |
| Number of new child cases | 14,981 | 8,629 | ▼ -42.4% |
| Number of new cases with G2D | 10,816 | 7,198 | ▼ -33.5% |
| Number of multibacillary (MB) cases | 130,058 | 85,686 | ▼ -34.1% |

## New case detection in global priority countries

New cases detected in the 10 countries with the highest number of cases (see chart at right) account for 112,056 cases or 88% of all new cases globally. For most of these countries, the number of new cases detected in 2020 was significantly lower than the number in 2019. DR Congo and Somalia were exceptions: both countries detected more new cases in 2020 than in 2019. Somalia’s revitalized national program detected over 2,000 new cases both years, which is a notable sustained increase in comparison to 107 cases detected in 2015.

In recognition of challenges faced by national leprosy control programs in the context of the COVID-19 pandemic, WHO has developed and published two guidance documents to assist with decision-making about whether and how to proceed with essential services and critical activities such as active case-finding.[2,3]

**Comparison of 2019 and 2020 data for countries with highest number of new cases**



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[1] World Health Organization, “Global leprosy (Hansen disease) update, 2020: impact of COVID-19 on global leprosy control,” *Weekly epidemiological record* 96, no. 36 (Sept. 10, 2021): 421-444, https://www.who.int/publications/i/item/who-wer9636-421-444.

[2] World Health Organization, “Considerations for implementing mass treatment, active case-finding and population-based surveys for neglected tropical diseases in the context of the COVID-19 pandemic” (July 27, 2020): 1-8, https://www.who.int/publications/i/item/WHO-2019-nCoV-neglected-tropical-diseases-2020-1.

[3] World Health Organization and the United Nations Children’s Fund, “Community-based health care, including outreach and campaigns, in the context of the COVID-19 pandemic” (May 5, 2020): 1-39, https://www.who.int/publications/i/item/WHO-2019-nCoV-Comm_health_care-2020.1.

VIEWPOINT

**Dr. Claudio Guedes Salgado**

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**Director of Health Surveillance, Belém, Pará, Brazil**

# Viewing disruption as an opportunity to rebuild

Between 1989 and 1998, the number of new cases per year of Hansen's disease (HD) in the world increased from 576,361 to 805,000. This increase occurred in the context of the World Health Assembly's 1991 resolution to "eliminate leprosy as a public health problem" by the year 2000 and associated efforts to train health professionals to facilitate HD diagnosis.[1]

However, since the World Health Organization (WHO) declared achievement of "elimination as a public health problem," the number of new cases counted each year plummeted to 202,195 in 2019. The number of new cases detected worldwide plunged to 127,396 in 2020 during the SARS-CoV-2 pandemic,[2] leading the HD community, persons affected by HD, and health care professionals to realize the worst moment of the last 20 years for HD control. Even before the pandemic, mathematical models indicated that we may now have more than 4 million people waiting to be diagnosed.[3] This huge reduction in the number of new cases in the last two decades can be ascribed to an untested declaration of HD "elimination." Misunderstood to mean "eradication," the "elimination" declaration is associated mainly with a loss of expertise about the disease, which has actually led to a different kind of elimination: the elimination of HD diagnosis.

Cases showing few symptoms remain undiagnosed for years, and so originate the new few classic cases still diagnosed. Asymptomatic cases are usually contacts of undiagnosed and untreated HD patients who are not correctly examined because of the lack of expertise and laboratory tools necessary to identify, classify, and define those who need early treatment for latent HD. Furthermore, among well-examined contacts of HD patients there are those positive for acid fast bacilli in slit skin smear, anti-PGL-I IgM serology or RLEP RT-qPCR, or those with nerve damage detected only by electroneuromyography or ultrasound.[4,5,6] A group of "healthy" contacts may even have two or more of these parameters altered. Despite these issues in diagnosis, WHO's present proposal is to give a single dose of rifampicin (SDR) to all of them,[7] a policy that has polarized many of us in the HD clinical community.[8]

The issues are not limited to problems of diagnosis. There are persons affected by HD receiving insufficient treatment (mostly borderline or lepromatous leprosy patients) who may need more than 24 months of multidrug therapy (MDT) and those with MDT failure, who need other drug regimens that are not available to them. These drug-related treatment issues, which are accepted for other diseases like tuberculosis,[9] are not currently acknowledged by WHO.

Something good can come from the disruption wrought by the SARS-CoV-2 pandemic crisis if we rebuild the HD technical program based on the following pillars:

1) Implement mandatory surveillance that relies at least on clinics, serology, and molecular biology. Communities surrounding former colonies and hot spots based on data of the last 20 years should be the initial targets.
2) Make serology, RT-qPCR, electroneuromyography, and ultrasound available to patients and contacts for diagnosis and follow-up.
3) Develop and make available new treatment regimens using other antibiotics for when a patient does not respond properly, although MDT may continue to be used as the first line scheme to treat patients and when necessary use for longer periods.
4) Make corticoids and thalidomide widely available for taking a patient out of a reaction crisis. For patients who require treatment for longer periods, whether for persistent reactions or worsening of nerve function signs/symptoms or pain, develop other drugs and new concepts.
5) Make surgery, orthotics, prostheses and other supportive equipment or human assistance available for patient follow-up when incapacity occurs.

These topics should be among the new global HD targets for Neglected Tropical Diseases in the WHO roadmap 2021-2030. All the matters pointed out here may be discussed under the umbrella of human rights as well, including the right of a person affected by HD to know whether they have really been cured of this complex disease.

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[1] Salgado et al. (2018). https://doi.org/10.1016/S1473-3099(18)30012-4.
[2] WHO (2021). https://www.who.int/publications/i/item/who-wer9636-421-444.
[3] Smith et al. (2015). https://doi.org/10.1371/journal.pntd.0003658.
[4] Barreto et al. (2012). https://doi.org/10.1590/S0074-02762012000900011.
[5] Dos Santos et al. (2017). https://doi.org/10.1371/journal.pntd.0006086.
[6] Da Silva et al. (2021). https://doi.org/10.1371/journal.pone.0251631.
[7] WHO (2020). https://apps.who.int/iris/handle/10665/336679.
[8] Lockwood et al. (2018). https://doi.org/10.1371/journal.pntd.0006403.
[9] Ginsberg et al. (2007). https://doi.org/10.1038/nm0307-290.

LETTER

**Yohanna Abdou**
**Representative, IDEA Niger**

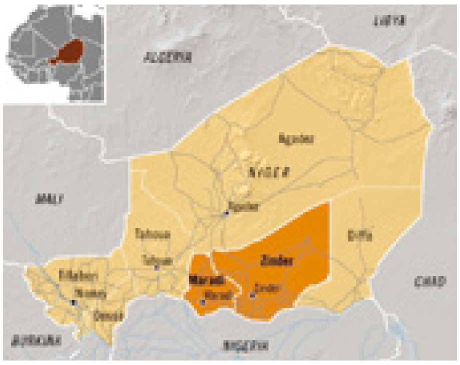
IDEA is the first international advocacy organization led primarily by individuals who have personally faced the challenges of leprosy.

**http://www.idealeprosydignity.org**
**https://www.facebook.com/Association-IDEA-104377407704513/**

# Progress in Maradi and Zinder regions of Niger

Niger is a West African country with a population of approximately 22 million people located in a semi-arid region known as the Sahel. We must deal with a fragile context that includes water-related challenges such as cyclic flood, drought, and insufficient rainfall along with epidemics of diseases such as malaria, meningitis, and, recently, COVID-19.

According to the standard of less than 1 case per 10,000 population, Niger eliminated leprosy (Hansen's disease) at the national level in 2002. However, for the past five years more than 300 cases have been diagnosed each year. Lack of adequate resources for leprosy and disability services along with prevailing negative attitudes result in poor leprosy control, high levels of disability, and stigma and exclusion of persons affected by the disease.



“Niger case study provinces reference map” by Hugo Ahlenius, UNEP/GRID-Arendal, is licensed under CC BY-NC-SA 2.0. Available at www.grida.no/resources/6745.

During recent field visits to Maradi and Zinder, persons affected by leprosy testified that it was not the number of diagnosed or deceased persons due to COVID-19 that caused the most pain. Rather, it was the social and economic changes related to management of the disease that had the most negative impact. For example, a government order to minimize gathering for meetings prevented self-help groups from holding their regular meetings every two weeks. These meetings are where they handle borrowing and reimbursement of revolving funds, and so their ability to engage in income-generating activities was affected.

IDEA Niger conducted a community support project with help of The Leprosy Mission using a Sasakawa Health Foundation grant. The support helped people to increase knowledge and awareness of leprosy, improve hygiene and sanitation, and generate income through small businesses or raising animals.

The joint project strengthened self-care groups. With the knowledge gained from the activities, members began urging one another to demonstrate good hygiene practices, such as taking care of their hands and feet, applying ointment, and avoiding wearing dirty clothes.

Life stories collected during the monitoring of activities are very encouraging. Beneficiaries testified that the support they received helped them to feel that they could deal confidently with this period of COVID-19. Adopting good hygiene, fully embracing self-care, and also conducting small activities that generate income forced respect. I can testify that this could lead to stigma reduction and health improvement.

Supporting self-care groups in collaboration with a health care center in Zinder's Kara Kara district (June 2021).

A woman practicing self care as part of IDEA Niger's activities in Maradi (May 2021).

In Zinder, sharing information about the importance of washing hands (June 2021).

VIEWPOINT

**Bill Simmons**

**Chair, Global Partnership for Zero Leprosy**
**https://zeroleprosy.org**

**President & CEO, American Leprosy Missions**
**https://www.leprosy.org**

# GPZL paves a new path towards zero leprosy

June 15, 2012, was the day I first met Yohei Sasakawa. We met in his offices in Tokyo where we shared our dream of accomplishing the goal of freeing the world from the infection and stigma of leprosy. That day I think we gave each other a gift. I recall Mr. Sasakawa saying that he was inspired and refreshed by my perspective on the last mile of the work to end leprosy. For my part, I was energized by this man who had given so much of his life to those impacted by this disease, and who still had hope of reaching the finish line. We agreed it would take something new, and that something came along six years later.

Yohei Sasakawa and Bill Simmons at their first meeting (Tokyo, 2012).

The last mile of disease elimination requires a new path forward, on that we both agreed. The Global Partnership for Zero Leprosy (GPZL) has paved this new path toward the shared vision of no disease, no disability, and no discrimination or stigma. Formed in 2018, GPZL facilitates collaboration to support national programming, advance leprosy research, and mobilize resources needed to achieve zero leprosy.

Beginning in 2018, GPZL brought the leprosy community together and the Sasakawa Health Foundation has been there from the beginning. GPZL has developed the Zero Leprosy Country Model, which offers customizable tools for countries to address local needs. We reached agreement on the Zero Leprosy Research Agenda, which outlines the research topics we need to address in order to end leprosy. When COVID-19 disrupted leprosy services, we convened the global community of people who have experienced leprosy and other experts to address unmet needs. Now we are in the exciting stage of collaborative action: putting these developments into practice.

Each country's path to zero leprosy is different. We have partnered with 11 countries to review leprosy activities and design country-owned roadmaps and action plans. We have conducted reviews alongside the National Leprosy Programs of Nepal, Ghana, Côte d'Ivoire, Uganda, and Mozambique. We look forward to continued collaboration with our current partners and to new partnerships in the coming year.

GPZL has also taken the research agenda forward through prioritization and landscaping of current projects. The leprosy research community has a wealth of expertise, and now we have a new way of working together. This year, GPZL is hosting workshops for researchers to further develop plans to approach the research agenda priorities. Alongside country work and research, we are also mobilizing national and international resources to beat leprosy and support the care and rights of people who experience leprosy.

We believe that zero leprosy can be achieved, and this new path forward has renewed our community's commitment to this belief. From that moment in June of 2012, when Mr. Sasakawa and I both expressed our desire to disrupt the current situation to reach the finish line, I am pleased to say that our community has made great progress. Together, we can cross the last mile and realize a world with no leprosy. GPZL is precisely the vehicle to get us there. We have only now to walk the road in partnership alongside all those who have joined this effort, and we will indeed one day see our shared visions fulfilled.

The GPZL review team, in partnership with the National Leprosy Program of Mozambique, conducts a focus group with community members in Nampula Province (October 2021). Photo credit: Ricardo Franco.

REPORT

**Erei Rimon**
**National Leprosy Elimination Program Manager**
**Republic of Kiribati**

Kiribati (pronounced "Kiribas") is an independent republic composed of 33 coral islands straddling the equator in the central Pacific Ocean. As of 2020, the estimated population of Kiribati was 119,446 people.

# Leprosy in Kiribati

Kiribati is among the three remaining countries in the Pacific region yet to achieve the World Health Organization (WHO) target of reducing the prevalence of leprosy cases to less than 1 per 10,000 population at the national level. Each year, the leprosy program has detected more than 100 new cases, which gives a prevalence rate that is more than 10 times higher than the WHO elimination target. Active early case detection activities — including household contact screening, population screening, school screening, awareness campaigns, and a skin clinic — are conducted across the country.

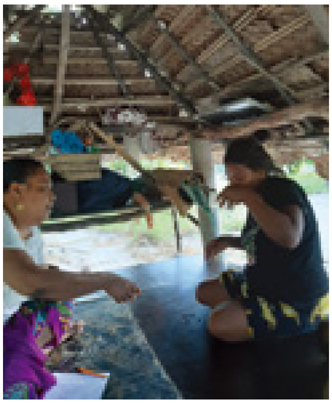
## Impact of COVID-19

Kiribati has not had any cases of COVID-19. However, one of the impacts of the pandemic was that the country closed home visits as a precaution for a period of three weeks. This meant that activities such as contact tracing and Post-Exposure Prophylaxis (PEP) were placed on hold for that period of time. However, once the shutdown was lifted we were able to resume promptly. There have been delays in funding from some of our donor partners, but the PEP project and routine work has continued largely unaffected. Our active early case detection activities found more new cases in 2020 than they did in 2019.

## Challenges

As an ongoing issue unrelated to the pandemic, staff shortages affect planning and implementation of activities. Completing activities within a specified time frame is especially challenging. With additional staff, leprosy services in Kiribati could be improved.

In addition to staff shortages, delays in funding affect the leprosy program's ability to complete activities according to an annual work plan. There is a chain reaction where delays in funding lead to delays in implementation, which then cause delays in completion. The national program is committed to working with its donor partners so that these delays can be reduced.



Giving single-dose rifampicin to household contacts.

School screening for leprosy.

Update training for South Tarawa health staff led by a local dermatologist.

Assessing a lesion on a newly detected leprosy patient.

SPOTLIGHT

# Accredited Social Health Activist (ASHA), a driving force behind India's public health system

Contributed by World Health Organization (WHO) India

Under India's National Health Mission, every village in the country has a trained female community health worker who is both selected from the village and accountable to it. These women have the title Accredited Social Health Activist (ASHA), and they are trained to work as an interface between the community and the public health system. They are responsible for mobilizing the community and facilitating access to health services at both primary health centers as well as sub-centers closer to the village.

Ritu, an Accredited Social Health Activist (ASHA) working at the community level in Uttar Pradesh, India. Photo courtesy of WHO India.

Here we introduce Ritu, an ASHA based in Nayagaon village, Gautam Buddha Nagar district, state of Uttar Pradesh. During the COVID-19 pandemic, she supported efforts to create awareness about the new disease and assisted in screenings and referrals in addition to continuing to perform routine duties. For leprosy patients, she provided multidrug therapy (MDT) drugs at their doorstep, ensuring regular treatment.

Leprosy has such varied presentations that it is useful for ASHAs like Ritu to have visual aids to help everyone learn to recognize the signs and symptoms of the disease. When everyone knows what to look for, community screenings more reliably result in early detection and treatment. ASHAs also need information leaflets and brochures to demonstrate how persons affected by leprosy should take care of their hands, feet, and eyes, and recognize complications. These materials help persons affected by leprosy and their families to follow through on the continuous care necessary to prevent development of disabilities. Efforts to train and empower ASHAs, who serve as frontline health workers, bring rich dividends in terms of strengthening the health system at the community level.

Illustration from flip chart titled "Leprosy is curable" designed to assist ASHAs in explaining the disease and the importance of early detection. Published by WHO India and India's National Leprosy Eradication Programme (NLEP) with the support of the Sasakawa Health Foundation.

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LEPROSY
HANSEN'S DISEASE
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