

# FOR THE Elimination OF Leprosy

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



Health Secretary B.P. Sharma addresses the National Stakeholders Meeting for Leprosy-Free India in New Delhi on 12 March 2015.

**MESSAGE** **CONTENTS**

## Our Work Is Gandhi's Vision

Since last year, there have been a number of endeavors to stimulate those involved in the fight against leprosy in India to greater efforts. A mid-term evaluation of the 12th Five-Year Plan of the National Leprosy Eradication Program has been carried out and the results are to be published soon.

In March, the annual conference of state leprosy officers took place in Delhi, organized by the Ministry of Health and Family Welfare. This was followed by a national stakeholders' meeting jointly supported by the ministry, the WHO and The Nippon Foundation that brought together individuals and organizations, including the Association of People Affected by Leprosy (APAL), that are working on leprosy elimination and related human rights issues.

Together with APAL, what I and The Nippon Foundation are doing now in India is not only moving against the disease and the discrimination it causes but also seeking to increase pensions, enhance children's education, provide microcredit and take other steps to improve living standards

for people affected by leprosy and encourage social change. Speaking at the stakeholders' meeting, I referred to Mahatma Gandhi's Constructive Program for building a new India, in which he devoted section 17 of his manifesto to leprosy. I also quoted some words of his: "If you can transform the life of a patient or change his values of life, you can change the village and the country." I sincerely hope our work can achieve this.

Last year I had the opportunity to meet twice with Prime Minister Narendra Modi. On both occasions, I expressed my hope that he would take the lead in resolving leprosy issues. The prime minister, who is a native of Gujarat State — as was Gandhi — gave a positive response and I look to him to show the way.

I am getting on in years, but my determination to fight against leprosy is undiminished. I shall be happy if I can continue this fight alongside all concerned until my final moments. Let us put our backs into this work and get the job done.

— Yohei Sasakawa, WHO Goodwill Ambassador

<b>Message</b>	<b>1</b>
<b>Report</b>	
Shared passions	<b>2</b>
<b>Voices</b>	
Three perspectives on restoring family ties	<b>3</b>
<b>Column</b>	
Breaking boundaries By Jan van Berkel President, ILEP	<b>4</b>
<b>Ambassador's Journal</b>	
Switzerland, India	<b>6</b>
<b>News</b>	
Law Commission of India drafts anti-discrimination bill	<b>8</b>
<b>From the Editors</b>	<b>8</b>

# Shared Passions

International gathering forges bonds during three-day retreat in Japan.



Animated discussions at Hotel Brush Up

A three-day retreat held at the end of January near Mt. Fuji was an opportunity for people affected by leprosy and supporting organizations from around 10 countries to get together in a relaxed atmosphere, share experiences and strategize.

The retreat was organized by Sasakawa Memorial Health Foundation, taking advantage of the launch in Tokyo of this year's Global Appeal to End Stigma and Discrimination against People Affected by Leprosy, which saw a number of invited guests come to Japan for the occasion.

Before arriving at the wonderfully named Hotel Brush Up in Gotemba, Shizuoka Prefecture, participants called at two nearby sanatoriums. National Sanatorium Suruga was the last leprosarium to be established in Japan, opening in 1945. It was conceived during World War II to treat Japanese soldiers who developed leprosy at the front. Of the 65 remaining residents, with an average age of 83, eight are former soldiers.

Koyama Fukusei Hospital is Japan's only remaining private sanatorium for leprosy and now also serves as a general hospital and hospice. Founded in the late 19th century by French Catholic missionaries, it is home to seven people affected by the disease. One of these is Tokio Fujiwara, who said he had first learned of a cure for leprosy by reading *Miracle at Carville*. He was thus delighted to chat with one of the visiting group, Jose Ramirez, Jr., who had been treated at the Carville sanatorium in the United States and knew author Betty Martin well.

## BUILDING PARTNERSHIPS

The retreat considered two themes: strengthening the participation of people affected by leprosy in leprosy services, and building partnerships for sustaining leprosy work and utilizing insights bequeathed by the disease experience. Some

interesting examples emerged from each.

In Ethiopia, ENAPAL (the Ethiopia National Association of People Affected by Leprosy) is not so much strengthening leprosy services but actually creating them in areas where government leprosy services are lacking, and teaching government health workers about leprosy.

In Indonesia, PerMaTa says it refers many suspected cases to health officials. This organization of people affected says of its ability to detect cases,

"We know by 'smell', by experience," but finds itself frustrated at times by what it says is the authorities' passive approach in the face of PerMaTa's activism.

In Brazil, a search for new partnerships led MORHAN (the Society for the Reintegration of People Affected by Hansen's Disease) to an association of sex workers. MORHAN trained them to recognize symptoms of leprosy in their clients and what to tell them. "They were happy to be approached — no one had ever asked for their help before — and they detected more cases than doctors," said Artur Custodio.

**"Don't talk about leprosy; talk about what it means to be a human being."**

In China, where JIA (Joy in Action) runs work camps in leprosy recovery villages to improve the residents' quality of life, Ryotaro Harada believes the way to appeal to new partners is to shift the focus away from the disease itself to themes such as resilience and survival. "Don't talk about leprosy; talk about what it means to be a human being," he said, adding that JIA is now starting to interest companies in the potential of work camps as opportunities for team building and self reflection.

Putting in an appearance on the final morning was Misao Ojika, the head of the Suruga sanatorium residents' association, who had been prevented by a cold from joining the proceedings earlier. He said he was delighted to meet so many people committed to leprosy work. "I couldn't understand what you were saying in English, but I could feel your power and passion," he said. "That makes me very happy." ■

# Restoring Family Ties

What it means to find out who you really are and where you came from.

Between 1945 and 1982, 1,147 children were born in Sungai Buloh leprosy settlement in Malaysia. Regulations dictated that if the parents could not find a relative or friend willing to take the infant within six months, it would be placed in a children's home or sent out for adoption. In later life, some of those children have come back in search of their biological parents after learning of their true identity. Others remain unaware of their origins, or reluctant to acknowledge them, even as their aging parents yearn to see them again.

Care & Share Circle is a non-profit organization formed by Eannee Tan and friends in 2011. It helps reconnect people still living in Sungai Buloh with their children. Among those Eannee has helped is Noraeni Mohamed, who was born in Sungai Buloh to Chinese parents and adopted as a child.\* Earlier this year, Eannee, Noraeni and Noraeni's daughter Nadzirah Ahmad Basri spoke at a series of symposiums in Japan about their experiences.



(L to R) Eannee Tan, Nadzirah Ahmad Basri, Noraeni Mohamed

**Eannee Tan:** Our mission is to reunite former leprosy patients and their descendants through all possible channels. In the end we hope to empower them with knowledge and courage to preserve their family history.

Not all descendants are able to meet their biological parents while they are still alive. Madam Noraeni strove for years to trace her origins, but her mother was already in her grave by the time she tracked her down.

Madam Noraeni has stood up for her real identity and has assisted others to find their origins. She is definitely a role model for those who are still hiding their connection with Sungai Buloh due to the social stigma attached to leprosy. Together, we have co-authored a book, *Reunion at the Graveyard*. With this book and a documentary, *Children of Sungai Buloh*, we hope to encourage more descendants to come back and trace their roots while their parents are still living.

**Noraeni Mohamed:** I was adopted by a Malay couple who were Muslims. This couple did not have any children of their own. In an effort to keep the truth about my birth a secret, they gave me a Malay name — Noraeni Mohamed.

The day after my adoptive mother passed away, I found my adoption certificate among her things. My search for my true parents began in 2006. After some initial progress, I had to suspend my efforts to nurse my husband, who had cancer.

At last, on December 18, 2009, I saw my mother's face for the first time. I am very thankful to God for letting me know how my mother looked, even though it was only via a photograph on her gravestone.

I had no hesitation in revealing myself as the daughter of a Hansen's disease patient, nor was I afraid of being scorned as I was confident that myths about the disease were far from the truth.

My religion, Islam, teaches me to obey and to do good to one's parents. I didn't have this chance.

All parents deserve the right to be loved and respected by their children. It is absolutely cruel to deny them the right to bring up and care for the children they gave birth to. Our lives would be chaotic if there was no family line. That is one of

the reasons why I wrote *Reunion at the Graveyard*: so that my children, grandchildren and great grandchildren will not forget their ancestors.

**Nadzirah Ahmad Basri:** I am very proud to let the world know that I am the grandchild of a Hansen's disease patient. All my five brothers and late father supported my mother's search for her lost family. God has destined that we are helping to fight for the rights snatched away from Hansen's disease patients.

In my opinion, the main need of the Sungai Buloh residents is to be accepted by the public. They are former leprosy patients who have the same rights as other Malaysian citizens. They should also be reunited with their families because it is cruel to separate parents from their children and other family members. I appeal to the public to help in whatever capacity to reunite such families.

At the same time, I would like to call upon all individuals who were born in Sungai Buloh and adopted by others to come forward and fulfil the dreams of their parents, many of whom are still waiting desperately for their loved ones to come back. Finding out one's real identity is a basic human right worth fighting for. ■

## FOOTNOTE

\* Eannee began her work with residents of Sungai Buloh prior to 2011. Her first contact with Noraeni was in 2009.



# Breaking Boundaries

ILEP adopts new strategy and decides to learn from and share with other diseases.

“We started self-help groups so patients were motivated to keep with the treatment and to learn self-care. But we found they can do more than that. They can support each other to fight stigma,” says Sunita.

She should know. For over 20 years this nurse and mother of three has been working in community health care in Bihar, northern India.

Because self-care practices — washing the limbs and massage — are similar for lymphatic filariasis and leprosy, Sunita and her colleagues at the NGO Lepra brought together patients suffering from these diseases in self-care groups. Slowly, they have built confidence to confront the prejudice against both these neglected tropical diseases (NTDs).

The International Federation of Anti-Leprosy Associations (ILEP) learned from such front-line experiences of breaking boundaries between diseases in devising our new strategy — “Achieving a World Free from Leprosy.”

The challenge is clear: progress on leprosy is just too slow. Numbers of new cases are not diminishing significantly. Lack of early detection and treatment means that this curable disease is still blighting many lives. Among children alone, some 20,000 contract the disease every year and an unknown number have already developed a lifelong impairment

that may well subject them to discrimination because of the stigma of leprosy.

## LEARNING FROM OTHER NTDs

Our members challenged us to make a step increase in our collaboration to find better ways to stop the transmission of leprosy, to prevent disability due to leprosy and to break the barriers that too often exclude children, women and men affected by leprosy and their families from society. We agreed early on that our mission was still to achieve a world free from leprosy, but that this could be better achieved by learning from other NTDs, while sharing leprosy’s learning with them.

**Our members challenged us to make a step increase in our collaboration.**

NTDs are diseases of poverty. As Dr. Wim van Brakel of Netherlands Leprosy Relief says of his work in Nepal: “In poor communities you find several NTDs. Most children in Nepal I diagnosed with leprosy also had round worm or hookworm. So a de-worming treatment is standard.”

Such insights have led to innovative methods of case detection. A Brazil schools program screened children for both worms and leprosy. Fondation Raoul Follereau in West Africa supports case detection for Buruli ulcer and leprosy.

Linkages between diseases inform research. The Leprosy Research Initiative (LRI) of ILEP members is supporting a study on the impact of helminth infestation on the immunology of leprosy. Linkages can also lead to joint action. A recent workshop in Utrecht, Netherlands, brought together organizations working on leprosy and several other NTDs to look at working together on prevention of disabilities, stigma reduction and inclusion, accessing funding and combining treatments.

Organizations working in other NTDs are keen to learn from leprosy regarding morbidity management, disability prevention and stigma reduction. Leprosy organizations have a longer history of self-management and self-care groups, which can be applied to all patients with wounds or skin problems. Plus, as Sunita explains, such groups can also develop solidarity to fight stigma.

**AUTHOR:**  
Jan van Berkel



Jan van Berkel is president of the International Federation of Anti-Leprosy Associations.



Moving forward: ILEP’s new strategy

## QUOTE

“The rising profile of the NTD agenda presents opportunities for collaboration on cross-cutting issues and intervention-based approaches.”

— From ILEP Strategy 2015-2018

### TACKLING STIGMA

Leprosy has been stigmatized since ancient times — and still is. Research carried out by Lepira in Bangladesh in 2014 showed that 32% of those interviewed would refuse to travel with people affected by leprosy and 29% would refuse to buy from that person.

Some 10 other NTDs also have published evidence that their diseases are stigmatized. But the leprosy field has gone further in tackling the issue with a set of human rights principles and guidelines on reducing stigma against people affected by leprosy and their families.

It also has a strong history of people affected by leprosy claiming their rights as I saw in Japan this January when I attended the tenth Global Appeal to End Stigma and Discrimination against People affected by Leprosy. I met women and men who successfully campaigned for repeal of Japan’s leprosy laws and in 2001 won compensation for being deprived of their human rights as a result of the state’s isolation policy.

An LRI and Sasakawa Memorial Health Foundation-sponsored trial of stigma reduction interventions in Indonesia that concluded in 2014 showed major improvements in the lives of children, women and men affected by leprosy. In addition, negative attitudes against leprosy in the community had reduced significantly. These experiences are worth sharing with other NTDs.

### TIME FOR CHANGE

Gandhi said, “We need to be the change we wish to see.” At ILEP we have changed ourselves. To ensure that as an organization we include people affected

by leprosy, we are setting up an Advisory Panel of women and men affected by leprosy, which, like our Technical Commission, reports directly to the top decision making body in ILEP, our Members Assembly.



New CEO Tanya Wood

We have a new strategy, a new CEO, Tanya Wood, and a new home in Geneva, where we have moved to be more nimble at creating a world free from leprosy. We want to learn from and share with those working on other diseases and to ensure that leprosy is not left behind when new health

initiatives are developed. We also aim to link better with the WHO, its Global Leprosy Program and NTD department, and relevant parts of the United Nations. Recently, the Rapporteur on Health made a statement on World Leprosy Day, while UN Women tweeted in support of ILEP’s report on the triple jeopardy of women and girls affected by leprosy.

Technical collaboration and support for government leprosy programs has been ILEP’s strength and our new Global Technical Policy Director, Dr. David Lai, will be based in Delhi to ensure that learning is spread widely among practitioners.

What has not changed is ILEP’s focus on leprosy. But our impatience to be more effective is causing us to learn from and share with other diseases, just as Sunita has taught us. ■

### ABOUT ILEP

The International Federation of Anti Leprosy Associations (ILEP) is a federation of 14 international non-governmental organisations. ILEP works to stop leprosy transmission, end disability due to leprosy and break barriers to inclusion for people affected by leprosy. Its work is supported by a Technical Commission of world experts on leprosy and an Advisory Panel of Women and Men affected by leprosy.

Members co-ordinate their work in 63 countries, where they spend some \$60 million on 700 projects and around \$US2.5 million per year on leprosy research. They work with some half a million girls and boys, women and men affected by leprosy, with ministries and the World Health Organization; with Novartis, which is

providing anti-leprosy drugs for free; The Nippon Foundation and other philanthropic trusts; with NGOs and governments and with the support of some 500,000 individual donors.

ILEP was founded in 1966. Members are AIFO Associazione Italiana Amici di Raoul Follereau, American Leprosy Mission, Austrian Leprosy Relief Association, DAHW German Leprosy Relief Association, Damien Foundation Belgium, Fairmed Switzerland, Fontilles Spain, Fondation Raoul Follereau, France, Lepira UK, MUPD Associação Portuguesa de Solidariedade Mãos Unidas Padre Damião, Netherlands Leprosy Relief, Sasakawa Memorial Health Foundation, Secours aux Lépreux - Leprosy Relief Canada, and The Leprosy Mission International.

# Geneva and New Delhi

A flying visit to Geneva to meet with members of the Human Rights Council Advisory Committee and a journey to New Delhi for the annual conference of state leprosy officers, followed by a national stakeholders' meeting.

## SWITZERLAND (FEBRUARY 26-27)

In February I made a short visit to Geneva to meet with members of the Human Rights Council Advisory Committee. My purpose was twofold: first, to update them on developments in the field of leprosy and human rights; and second, to solicit their support for the further work that will be needed to see that principles and guidelines referred to in the U.N. resolution on elimination of discrimination against persons affected by leprosy are fully acted upon.

My mission related to the Japanese government's plan to present a draft resolution at the 29th session of the Human Rights Council in June, requesting the Advisory Committee to conduct additional research into the circumstances of people affected by leprosy. The aim is to pave the way for the effective implementation of the principles and guidelines by governments and civil society.

Taking place in Geneva at the same time will be the fifth and final symposium in a series that the Nippon Foundation inaugurated in 2012 to publicize the U.N. resolution in different regions of the world. At the symposium, an international working group will issue its proposal for a sustainable mechanism for monitoring implementation of the principles and guidelines.



Dr. P.K. Gopal in Geneva

Joining me in addressing members of the Advisory Committee in Geneva were Professor Shigeki Sakamoto, a former member of the committee who helped to draw up the principles and guidelines, and Dr. P.K. Gopal, the president of IDEA India, who stressed the importance

of their implementation from the perspective of a person affected by leprosy.

I am most grateful to the Advisory Committee members for meeting with us and hearing what we had to say. I look forward to their further consideration of this issue.

## INDIA (MARCH 9-13)

In a world that sees some 215,000 new cases of leprosy annually, India accounts for nearly 60% of the total. Although the country achieved elimination

of leprosy as a public health problem at the national level by the end of 2005, new cases numbers have plateaued in the years since. India's new case detection rate is three times the global level, while the rate of Grade 2 disability among new cases is almost double (see chart).

At the sub-national level, one state and one Union Territory out of a total of 36 have yet to achieve the WHO goal of leprosy elimination, defined as a prevalence rate of less than 1 case per 10,000 population; at the district level, 140 out of 636 districts have yet to do so.

## State leprosy officers are key to the successful execution of the program.

The central government's National Leprosy Eradication Program (NLEP) is in the midst of its 12th Five-Year Plan, which aims to eliminate leprosy in all districts, strengthen disability prevention and reduce the stigma associated with leprosy. Part of the strategy relies on the involvement of ASHAs (Accredited Social Health Activists), who go door-to-door in search of new cases and receive incentives when a new case is confirmed and again when treatment is completed. But key to the successful execution of NLEP are the state leprosy officers (SLOs). The SLOs are responsible for executing the central government's strategy in their respective states and seeing that it is carried out effectively. It was to take part in the annual gathering of SLOs that I travelled to New Delhi this time, as well as to attend a meeting of national stakeholders for a leprosy-free India.

Addressing the SLOs conference, Dr. C.M. Agrawal, Deputy Director General, Leprosy, Ministry of Health and Family Welfare, drew attention to the challenges India still faces, including sustaining leprosy services at the peripheral level, and appealed to those states and districts yet to achieve elimination to redouble their efforts to do so.

WHO's representative in India, Dr. Nata Menabde, said mapping was needed to identify areas with large numbers of cases and where the disability rate and rates of leprosy in children were high. At the same time, she also stressed that until discrimination against persons with leprosy ends,



WHO's representative in India, Dr. Nata Menabde, lights the inaugural lamp at the start of the state leprosy officers' conference.



<b>THE BURDEN OF LEPROSY (2013)</b>	GLOBAL	INDIA	% OF GLOBAL
New cases detected (New case detection rate per 100,000 population)	215,656 (3.18)	126,913 (9.78)	58.85%
Grade 2 disabilities among new cases (Rate of G2 disability per million population)	13,289 (2.3)	5,256 (4.13)	39.55%
Children among new cases (Proportion among new Cases)	19,840 (9.2%)	12,041 (9.4%)	60.69%
Relapse cases	3,196	919	28.75%

Source: WHO

it cannot be said that elimination has truly been achieved.

For my part, I thanked the SLOs for their dedication and said I hoped to see a reduction in the disability rate, especially among children. I also expressed the hope that the services of people affected by leprosy could be actively utilized in these case-finding efforts. They, after all, are familiar with the symptoms and know the consequences if the disease is left unattended.

In their presentations, SLOs covered a wide range of issues, from the challenges of reaching tribal peoples in remote areas and the problems of keeping track of migrant populations to the fact that the post of district leprosy officer is vacant in some districts.

Many of the same participants attended the national stakeholders meeting that followed the two-day SLOs conference. They were joined by disability NGOs, media experts and others with ideas and suggestions on how to bring an end to leprosy and the discrimination it causes.

I was encouraged to hear Health Secretary Bhanu Pratap Sharma say that measures were needed to focus on so-called leprosy hotspots where many cases are concentrated and that he intended to come up with a sustainable strategy to address this.

Following wide-ranging discussions, participants endorsed a set of recommendations and agreed that these should form the basis of a concrete plan of action to be drawn up without delay.

Among the recommendations were to enhance new case detection activities, including special

approaches for underserved populations such as urban and tribal populations; strengthen referral services at all levels to manage complications and look out for and manage reactions and disabilities; identify and implement opportunities to involve persons affected by leprosy, such as in case-finding; and introduce mandatory training of leprosy program managers and service providers at state, district and block levels at central government and NGO training institutes for leprosy.

Together with the WHO, the Nippon Foundation is now planning to invite health ministers and health secretaries from India's endemic states, together with other stakeholders, to a Tokyo Leprosy Summit in July. The summit is to review the points raised at the meetings in Delhi and to unveil a plan of action based on the recommendations endorsed at the stakeholders' meeting in March. It is my hope that the summit will serve as a morale-boosting exercise that will reinforce a common sense of purpose to defeat leprosy and that the plan of action will be reflected in actual policy.

Although many challenges remain, I believe that one day it will be possible to realize an India without leprosy. This requires that people—above all, those in areas where the disease is endemic—are properly informed about the disease, go promptly to a health post or hospital if they suspect they might have leprosy, and are treated before disability sets in. Step by step, let us take the actions necessary ensure that every new case is identified early, treated and cured. It can be done. ■

# Act Now, India's Law Panel Urges

Calls on government to fulfill obligations to eliminate leprosy discrimination.



The Law Commission of India has drawn up draft legislation for eliminating discrimination against persons affected by leprosy, including the repeal or amendment of all laws with discriminatory provisions and an end to use of the term “leper” in official documents. The draft bill is annexed to Report 256 (“Eliminating Discrimination against Persons Affected by Leprosy”) submitted to India’s justice ministry on April 7.

In a covering letter, Commission Chairman Justice Ajit Prakash Shah observed that leprosy is now a completely curable disease, yet social stigma remains a major obstacle to uplifting the status of people affected by leprosy, while Indian laws continue to directly and indirectly discriminate against them. Although India has signed and ratified the U.N. Convention

on the Rights of Persons with Disabilities and was a member of the U.N. General Assembly that unanimously passed the December 2010 resolution on elimination of leprosy-related discrimination, he said that no action had been taken at central or state level to modify or repeal any of the legislation.

“Under the Constitution, the Union of India has both the obligation as well as the competence to enact a comprehensive law eliminating discrimination against persons affected by leprosy. This is now an urgent need,” he said.

The draft bill is designed to eliminate any discrimination or denial of equal treatment; to repeal and amend existing laws that negatively affect such persons or promote their segregation and discrimination; and to enable the state to discharge its obligations through affirmative action. Key provisions include those relating to land rights, employment, education and training opportunities, and freedom of movement. Among laws that would be repealed or amended are the Lepers Act (1898) and various laws that make leprosy grounds for divorce.

On terminology, the draft says that “‘leper’ and other such terms in national, regional and local languages shall be substituted by the term ‘persons affected by leprosy’ or any other term in the national, regional or local language that is synonymous.” ■

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### LAST RESTING PLACE

Elderly residents of Japan’s national leprosy sanatoriums are living reminders of a past policy that isolated people with the disease for life. As the numbers of the living decline, so the remains of the dead increase. Each year, urns are being added to the neat rows that fill the charnel houses of 13 national sanatoriums.

It was sometimes said that the only way to leave a sanatorium was as smoke from its crematorium chimney; yet even in death, some have never left. The charnel house at National Sanatorium Suruga is surrounded by 100 weeping cherry blossom trees. As of the end of January, it contained 310 urns, including those holding the ashes of 10 aborted fetuses that had been stored in the sanatorium’s laboratory. Although

residents lived under pseudonyms to protect their families’ reputations, in death they have been reunited with their true identities and each urn bears a real name.

When a resident dies, the sanatorium contacts the next of kin to ask what they wish to do with the remains. Many families refuse to accept them, although in recent years there have been more takers. In some cases, they never even knew of their relative’s existence.

Families are less reluctant to accept any savings the deceased might have accumulated from pensions and compensation payments for the state’s violation of their constitutional rights. As a staff member put it: “Sometimes they’ll take the money, but leave the bones.”