

FOR THE
**Elimination
OF Leprosy**

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



The Goodwill Ambassador joins schoolchildren participating in a leprosy awareness campaign in Jharkhand, India, on February 2, 2018. (see page 7)

MESSAGE

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Disability and Leprosy

The 13th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy was launched from New Delhi on January 30, the anniversary of Mahatma Gandhi's martyrdom and the date that India marks as Anti-Leprosy Day.

This year's appeal was supported by Disabled Peoples' International, a cross-disability organization active around the globe. Founded in 1981, it is committed to the protection of the rights of people with disabilities of any kind and to their full and equal participation in society.

Although the DPI's activities are extensive, Global Chair Javed Abidi says there hasn't been sufficient collaboration between the disability and leprosy communities to counter deep-seated prejudice toward persons affected by leprosy, nor has leprosy been taken up at disability meetings. It was as if people affected weren't recognized as disabled.

That said, there has been some overlap between developments in the disability movement and the efforts I have led to address leprosy's social dimension. Between the 1970s and the 1990s, several declarations and resolutions relating to the rights of persons with disabilities were passed at the United Nations. In 2010, meanwhile,

a resolution was adopted on elimination of discrimination against persons affected by leprosy and their family members, accompanied by principles and guidelines.

But none of these were legally binding. Therefore, the disability movement pressed on and in 2006 achieved the Convention on the Rights of Persons with Disabilities, which has transformed the situation. While it is not necessary for the leprosy community to follow exactly the same path, I believe it indicates the direction it ought to be moving in.

My aim is to realize an inclusive society in which no one is left out—be they persons affected by leprosy or those with any other disability. Making use of this year's Global Appeal, I wish to promote further awareness of leprosy, respect for human rights and progress toward a world without discrimination.

I have since learned the sad news of Mr. Abidi's passing. His untimely death is a loss for the disability rights movement. Let us ensure that the collaboration between the disability and leprosy communities that he was helping to foster forms part of his legacy.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Toward an Inclusive Society

Latest appeal aligns with disability movement for end to stigma and discrimination.



Delegates gather for a commemorative photo at the end of the launch ceremony.

The 13th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy was launched from New Delhi on January 30, 2018, endorsed by Disabled Peoples' International (DPI).

Since its inception in 2006, the annual appeal has been supported by a wide range of individuals and organizations, and this year's appeal added another influential voice to a growing list that includes faith leaders, parliamentarians, the legal, nursing and medical professions, and national human rights organizations.

Established in 1981, DPI is the world's first cross-disability organization. It promotes the human rights of persons with disabilities of any kind through full participation, equality of opportunity and development.

Under its global chair, Javed Abidi, DPI has been taking steps in partnership with The Nippon Foundation to reach out to persons affected by leprosy and facilitate their inclusion in the global disability movement. Its endorsement of this year's Global Appeal represents a further such step.

This year's appeal added another influential voice to a growing list.

Some 250 people were present at the launch ceremony, which opened with a performance by a choir composed of children living in a leprosy colony in Delhi. This was followed by a short video message from U.N. Secretary-General Antonio Guterres after which the audience heard from Goodwill Ambassador Yohei Sasakawa; DPI's Abidi; Forum of Parliamentarians for a Leprosy-Free India chairperson Dinesh Trivedi; U.N. Deputy High Commissioner for Human Rights Kate Gilmore; and the WHO's Regional Director for Southeast Asia, Dr. Poonam Singh, whose remarks were read out on her behalf. Also speaking were Vagavathali Narsappa, president

of India's Association of People Affected by Leprosy (APAL), and Tarun Das, chairman of Sasakawa India Foundation (S-ILF).

In her wide-ranging remarks, the U.N.'s deputy human rights commissioner noted: "Persons affected by leprosy and their families are not asking for special treatment—they are demanding equal treatment; for their legally binding, universal human rights to be fulfilled and for states to act decisively—and accountably—to fulfill their duties to this end."

She also stressed: "Rights are for the best and the worst of us; for each and every one of us; to the exclusion of none of us, in the interests of all of us."

FAITH IN YOUTH

S-ILF Chairman Das placed his faith in a new generation, citing the success of a three-day youth festival held prior to the appeal that brought together young people from leprosy colonies and college students. "Maybe my generation has failed (to end discrimination), but maybe youth can succeed," he said.

The organizers also received video messages from U.N. High Commissioner for Human Rights Zeid Ra'ad al-Hussein and from popular Indian actor Amitabh Bachchan, who quoted Mother Teresa's famous lines: "The greatest disease today is not TB or leprosy, it is being unwanted and uncared for. We can cure physical diseases with medicine, but the only cure for loneliness, despair and hopelessness is love."

With the speeches and messages concluded, representatives from DPI joined other dignitaries on stage for the reading of the appeal, which had been endorsed by over 90 DPI national member assemblies.

"We will work together with persons affected by leprosy to speak out and advocate for greater social participation," DPI pledged. "In working toward our common goal of an inclusive society, we will share knowledge and experience with persons affected by leprosy."

At a conference on leprosy and disability that followed the appeal, DPI did exactly that. (see facing page) ■

Know Your Rights

If you want to claim your rights, you have to know what they are, conference told.

In introducing the National Conference on Leprosy and Disability held in New Delhi on January 30 and 31, the global chair of Disabled Peoples' International (DPI) readily admitted that he had not known much about leprosy until coming into contact with the work of The Nippon Foundation.

Once Javed Abidi had familiarized himself with the issues, however, he made a commitment to bridge the gap he saw between the disability and leprosy sectors. "Our challenge is how to mainstream people affected by leprosy within the disability movement," he said.

Billed as a national conference, the DPI-organized event was given an international flavor with the participation of speakers from Bangladesh, Brazil, Myanmar, and the Philippines.

They included Faustino Pinto of Brazil's Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN), who asked: "Why should I allow a disease to determine how I am viewed by society?" and argued forcefully for dispensing with the term 'leprosy' because of its stigmatizing associations. "If you want to change discrimination, you have to change the way we speak about the disease," he said.

ENGAGING WITH THE COMMUNITY

Mohammed Kamal Uddin, ex-president of Bangladesh's Disadvantaged People's Association, detailed a strategy for combating discrimination and mainstreaming leprosy that ranged from educating family members and reaching out to local and national disabled people's organizations to lobbying the government to include leprosy in the nation's 2013 disability act.

He also spoke of the importance of engaging with community leaders and creating opportunities for people affected by leprosy to tell their stories, and of the powerful impression created by social workers shaking hands with and embracing people affected by leprosy.

Carmen Lucia Lopes Fogaca, president of the



Speaking out in Delhi

National Organization of the Physically Disabled of Brazil (ONEDEF) outlined the ongoing struggle for disability rights in her country. An important point was reached when "we started to talk for ourselves," she said. "We have come a long way, but we still have a long way to go to achieve an egalitarian society."

CAPACITY BUILDING

The second day of the conference included a training session for persons affected by leprosy undertaken by the Diversity and Equal Opportunity Centre (DEOC), designed to familiarize them with the landmark Rights of Persons with Disabilities Act, 2016. The new act brings India into line with its obligations under the Convention on the Rights of Persons with Disabilities and increases the number of disabilities recognized under the 1995 Persons with Disabilities Act from seven to 21, including leprosy.

Being disabled doesn't mean something is wrong with you. Disability is another diversity.

During the session, DEOC's Rami Chari drew her audience's attention to the distinction between the different approaches to disability underpinning the old and new acts. Under the 1995 act, society was considered 'normal' and the disabled 'abnormal', she said; under the 2016 act, which is based on the concept of equal rights, the problem lies with society if there are barriers—be they physical or attitudinal—standing in the way of full participation by persons with disabilities.

"Being disabled doesn't mean there is something wrong with you. Disability is another diversity—along with being tall or short, and the color of your skin," Chari said.

TAKE OWNERSHIP

After group discussions involving people affected by leprosy in which they identified the issues they felt were most pressing in their part of the country—land rights, access to benefits and entitlements, and awareness-raising among them—a final session reinforced the earlier messages about the fundamental nature of human rights.

"All disabilities are not equal, but there are equal rights," said DPI's Abidi in reference to the 21 disabilities listed in the new act. He urged persons affected by leprosy to familiarize themselves with their rights and take ownership. "If you don't claim ownership, you can't expect anything," he said. "This is as much your law as anyone else's." ■

Tigers and Goats

Retreat explores challenges to sustaining the activities of people's organizations.

People's organizations from five countries gathered in New Delhi at the end of January for a three-day retreat on sustainable people-centered partnership in leprosy. Organized by Sasakawa Memorial Health Foundation and chaired by Dr. Arturo C. Cunanan, chief of the Culion Sanitarium and General Hospital in the Philippines, the meeting touched on fundamental issues affecting the ability of NGOs and social movements to carry out their mission.

Taking part were the Association of People Affected by Leprosy (APAL), India; the Coalition of Leprosy Advocates of the Philippines (CLAP); HANDA Rehabilitation and Welfare Association, China; the Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN), Brazil; and Perhimpunan Mandiri Kusta (PerMaTa), Indonesia.

The gathering was a follow-up to an earlier retreat held in 2015 outside Tokyo that focused on sustaining leprosy services through the wider participation of people affected by leprosy and the involvement of new actors.



Putting heads together to plot a sustainable future

transparent and accountable, reliable and efficient.

3. Reliance on external funding

All the organizations are operating with limited resources and are reliant on external funding. There is a critical need to address the issue of sustainability and diversify their partnership base and sources of funding and income in the event that key donors withdraw support. "We have been given a wake-up call," said APAL's G. Venugopal.

4. Waning interest in leprosy

Funding for Hansen's disease programs is decreasing. Governments have only limited interest in and provide limited support for projects for and by persons affected by leprosy. The perception that leprosy has been "eliminated" has had a negative impact. "Leprosy is not a sexy issue at local government level," said PerMaTa's Paulus Manek. Yet new cases continue to occur, stigma continues to exist, and people are still developing lifelong disability as a result of leprosy.



Manek: There are people who rely on us.

Here are 13 talking points from the Delhi retreat:

1. Sustainability is for a reason

The mission of people's organizations requires long-term effort and commitment. From fighting discrimination, promoting social and economic empowerment, and raising awareness to counseling patients and their families, there is much to be done and people's organizations can fill the gaps that governments can't or don't cover. "There are people who rely on us. As long as there are issues to be addressed, we have to continue to exist," said PerMaTa's Paulus Manek. But not forever: "MORHAN was born to die," said Artur Custodio. "When we succeed in our mission, we are no longer necessary."

2. Partnerships are important

They allow organizations to cover more ground, have a bigger impact, share resources, learn from each other and encourage each other. But partnerships come with responsibilities, too—including being

We cannot agree with everything the government says and call it partnership.

5. Relationship with government

In the discussions on partnership, one of the most contentious areas was on what form the relationship with government should take. In China, government approval is very important, said HANDA's Michael Chen. In order to establish and maintain a reputation for integrity, HANDA is assiduous in complying with regulatory requirements to show that it can be relied upon. This is especially necessary in the Chinese context, where NGOs have "weak capacity, a low public profile and suffer from a lack of public trust," he said.

But for a social movement such as MORHAN, it is not possible to fulfill its role if it is in lockstep with the

government at all times, “The government does not allow our autonomy,” said Faustino Pinto—or, as APAL’s Venugopal put it more colorfully, “Partnership with the government is the partnership of a tiger and a goat.”

“Partnership is important,” said Pinto, “but sometimes we don’t always follow the same goal as the government, as many times the rights of the people are disrespected. We cannot agree with everything the government says and call it partnership.”

6. Leprosy’s negative image

Organizations reported a reluctance among companies and other potential sponsors to associate themselves with the disease because of its negative image. In Brazil, there is a “beauty culture,” said Pinto. “Companies don’t want to be linked to a disease such as Hansen’s disease.” MORHAN also noted that a crowd-funding campaign it had launched was doing poorly compared to another campaign running concurrently for animal welfare.

7. Sustainability requires a strategy

Organizations agreed that sustainability needs to be part of planning and that they need to be thinking about it now. “CLAP will die a natural death unless a strategy for sustainability is realized,” said Francisco Onde. Yet many of the organizations lack such a strategy and have limited or no capacity to develop one.

8. Capacity-building doesn’t come cheap

To develop a sustainability strategy requires investment. Are donors willing to invest in sustainability? Donors—and that includes government in particular—need to be persuaded of the importance and contributions of people’s organizations.

9. Advocacy is a hard sell

“Donors typically want to see their donations go directly to improving people’s lives, but we cannot always say that our work has had a direct impact on our stakeholders,” said APAL’s Vagavathali Narsappa. “A lot of what APAL does is advocacy work, and the results we are achieving are invisible. We can’t say

QUOTE

“A sustainable organization needs to be strong institutionally, financially and morally.”

– Dr. Arturo C. Cunanan



APAL’s Venugopal: Let us create a link between us



Acknowledging common goals and objectives

directly that pension increases are down to us. It is difficult to raise money for advocacy.”

10. Use outside experts as needed

Organizations of and for people affected by leprosy should not be afraid to turn to outside experts in order to fulfil their mission, including using experts to develop strategies for sustainability and fund-raising. Transformation poses challenges, however, such as how to retain one’s identity as an organization of and for the primary stakeholders while at the same becoming more professional.

11. Fund-raising requires funds

Fund-raising requires expertise, materials and a strategy, which all cost money. In addition, an organization may need to be audited before it can qualify for funds or be part of an income-generating project, and this can be a costly expenditure when resources are limited. Organizations will need to consider whether the pay-off justifies the investment.

12. Social enterprise is not for everyone.

Not every people’s organization has the capacity or capability to engage in social enterprise, nor is social enterprise alone a sustainability strategy. Having established its credentials, HANDA is paid by the government to enhance capacity of local NGOs, but believes that such social enterprise can only ever form part of its sustainability strategy.

13. A network of people’s organizations

There was agreement that the organizations represented were operating in different social, political, legal and cultural environments, but that they had shared goals and objectives in promoting the health and well being of people affected by leprosy, fighting discrimination and fostering dignity and social inclusion. They also found there was much they could learn from each other, as the discussions had shown. “Let us create a link between us, a network,” APAL urged. “There should be a formal network.” ■

Generating Awareness in India

The Goodwill Ambassador launches the 13th Global Appeal from New Delhi, and makes a field trip to Jharkhand.

INDIA (January 28 – February 4)

At the end of January I flew to Delhi for the launch of the 13th Global Appeal for the elimination of stigma and discrimination against persons affected by leprosy. This year, the appeal was endorsed by Disabled Peoples' International (DPI), a cross-disability organization that is reaching out to the leprosy community.

The occasion presented the chance for a small delegation including persons affected by leprosy to call on President of India Ram Nath Kovind. I am grateful to Mr. Tarun Das, the chairman of Sasakawa-India Leprosy Foundation (S-ILF), for making this possible. During the meeting, which was also attended by Mr. Dinesh Trivedi, the chairman of the Forum of Parliamentarians for a Leprosy-Free India, the president noted that India has made great strides to reduce the burden of the disease, but still has a long way to go. "Advocacy is critical," he said. "Let us join hands and work for a leprosy-free India."

I also took part in the National Conference on Leprosy and Disability, organized by DPI, which followed the Global Appeal. I was able to see for myself the actions being taken to form bonds between the leprosy community and the mainstream disability movement to advance the cause of an inclusive society.

From Delhi I travelled to Jharkhand State to meet with top state officials and other stakeholders to support efforts by the Association of People Affected by Leprosy (APAL) to improve the living situation of residents of leprosy colonies in the state and to learn more about the activities being taken by the central and state governments.

On arrival in the state capital, Ranchi, I met in succession with Health Minister Ramchandra Chandravanshi, Chief Minister Raghubar Das and Social Welfare Minister Louis Marandi. Accompanying me were national and state representatives from APAL as well as Dr. Anil Kumar, who is in charge of India's National Leprosy Eradication Programme.

APAL had drawn up a series of requests to the state



DPI's Javed Abidi (3rd from left) addresses the launch ceremony

government, which they presented to the ministers in the form of a petition. They backed this up with the results of a survey they had conducted of leprosy colonies in the state, giving the name, age and sex of every resident.*

Signed by APAL's state representative, Md Jainuddin, and its vice president, G. Venugopal, the petition called for the creation of an inter-departmental coordination committee "to solve issues related to us on a single table."

At each of the three meetings, the response from the state government was positive, with the health minister agreeing to attend a stakeholders' meeting later the same day in a show of support.

During my stay in Jharkhand I also visited several self-settled colonies in the state to see for myself the conditions in which persons affected are living and hear their hopes and concerns.

The first colony I visited was in the town of Ramgarh. It consisted of 56 households and had a population of 350, including 40 leprosy-affected persons. They are concerned about the future because they have no title to the land and worry what will happen to them if the area is redeveloped in connection with a project involving the nearby railway.

While few of the residents beg for a living, some I saw working should have been at school. One of the images that stays with me is of two young boys at work harvesting metal components from scrap, sitting in clouds of dust thrown up by their hammers.

From this colony I went to visit a school where students have received awareness training in leprosy as part of the Sparsh campaign (see sidebar), which I followed by a visit to a village. Next I called at a health center where I met with members of a self-care group and a dozen Accredited Social Health Activists (ASHA), who are so important to new-case detection efforts at the grassroots.



A young boy at work, harvesting scrap metal

FOOTNOTE

* The survey listed 56 colonies with a total population of 7,229 of whom 2,067 are persons affected by leprosy.



(Right) Md. Jainuddin addresses residents of Nirmala colony; (far right) a women's group at the Nirmal Gram complex



Next came a brief visit to Nirmala colony, a riverside colony that I called at on my last visit to Jharkhand in 2013. It had been subjected to flooding in the past but a wall has since been built to prevent a recurrence. In any event, the 230 residents are to be relocated to another colony where they will be provided with better housing as part of the steps Jharkhand is taking to improve the living conditions of persons affected in the state.

The colony they are moving to was my next destination: Indira Nagar. It was already dark by the time I arrived, but Mr. Jainuddin and I were able to report on our meetings with state leaders and convey the news that efforts were under way to see that colony residents can access their benefits and entitlements.

On my last full day in Jharkhand I traveled to Bokaro (known as “Steel City”) to visit the three colonies that make up the Nirmal Gram leprosy colony complex. It was a tremendous occasion, with a marching band greeting me at the entrance and speeches and dancing once I was inside.

I was impressed at the number of women’s

self-help groups that had been formed, with their representatives telling me that they wanted to generate funds for their children’s education and make a better life for their families. I was similarly struck by the enthusiasm of the youth group leaders that I met, who described the skills training they had undergone or hoped to receive, and their dreams and ambitions.

After the presentations and performances, I was taken on a tour of the colony complex. The three colonies have received support from S-ILF and are well-maintained. I was able to see a number of livelihood enterprises that had been started with the assistance of S-ILF, including a piggery and a poultry business.

As I walked around the complex, I recalled something the youth leaders had said earlier, which was that they would like to see the word “leprosy” removed from the name of every colony. I very much welcome this attitude coming from a new generation. It is the right direction to be moving in to further reduce stigma and promote social integration. ■

YOUNG AMBASSADORS

During my visit to Jharkhand State, I found myself looking into the eager faces of some 350 teenagers who had assembled in the grounds of the Gandhi Sonarah +2 High School. They had been taught about leprosy as part of the Sparsh leprosy awareness campaign initiated last year by India’s National Leprosy Eradication Program under Dr. Anil Kumar.

Sparsh (Hindi for “touch”) is an ambitious project devised by Dr. Kumar to reach out to all 600,000 villages

across India. It provides people with information about the symptoms of leprosy and its treatment, and seeks to dispel myths and misconceptions about the disease. The aim is to ensure that people who develop the disease feel able to come forward early for treatment, encouraged by their community, and do not suffer discrimination at the hands of their neighbors.

The campaign takes different forms: ASHA health workers visit homes and provide information; there are informative skits about leprosy in public spaces; people affected by the disease speak about their experiences; and school children who have been sensitized about leprosy pass on what they have learned to those around them.

Such advocacy is an important part of my own role as Goodwill Ambassador. I seek the political commitment of leaders at national and state

level to maintain efforts against the disease and the discrimination it causes; I speak to the public about leprosy through the media; and I address local communities.

There is only so much that one person can do, however. So when I heard the 350 schoolchildren I met in Jharkhand pledge in unison to pass on correct information about leprosy, I was greatly encouraged. “They become ambassadors,” the head teacher told me proudly. “This is a Gandhi school, so all students are committed to a leprosy-free India. It is an important mission of ours.” The Nippon Foundation is supporting a similar initiative with Junior Chamber International (JCI) India to educate youth about leprosy and give them the skills to educate others.

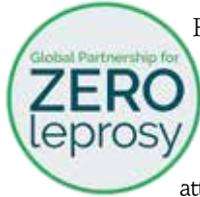
Instilling community awareness and participation is crucial. It helps to promote self-reporting and early diagnosis and treatment, and reduce stigma. I am happy to know these “young ambassadors” are playing such an important role.



With the “young ambassadors” of the Gandhi Sonarah +2 High School

Global Partnership for Zero Leprosy

Aims to accelerate progress toward a world without leprosy through innovation.



For the past decade, the annual number of newly diagnosed cases of leprosy has remained above 200,000. Now a new partnership is hoping to broaden collaboration, attract new funding and mobilize

scientific innovation to break transmission of the disease.

Launched in January, the Global Partnership for Zero Leprosy will coordinate action in three main areas: 1) accelerating research in new diagnostic and therapeutic tools, interventions and strategies to interrupt leprosy transmission; 2) mobilizing technical assistance and expertise to strengthen existing national programs; and 3) increasing advocacy and fundraising.

“By combining expertise and coordinating research and funding efforts, we will be able to

take advantage of new and innovative approaches to accelerate progress toward the elimination of leprosy,” said Dr. Ann Aerts, head of Novartis Foundation, one of the organizations behind the new partnership.

Other members include the International Federation of Anti-Leprosy Associations (ILEP) and the International Association for Integration, Dignity and Economic Advancement (IDEA), with representation from national leprosy programs, scientific organizations and the academic community, and support from the World Health Organization.

The secretariat is hosted by the Task Force for Global Health, a U.S.-based NGO working to improve health conditions for vulnerable populations.

For more information: www.zeroleprosy.org

VALLEY OF HOPE STORY GALLERY

A story gallery focusing on the lives of residents of the former Sungai Buloh Leprosy Settlement in Malaysia was launched on February 25, 2018. Featuring photos, artifacts and more, it preserves the stories and memories of residents of the settlement, which opened as a model leprosy colony in 1930 during British colonial rule of Malaya.

The gallery was established by the Sungai Buloh Settlement Council and financed by a crowd-funding project dubbed “You Are the Hero.” Today there are around 150 persons affected by leprosy still living in the former settlement, which was also known as Valley of Hope.

“We feel that future generations should know this history, because it shows the darkest and most

beautiful aspects of human nature,” said Eannee Tan, who spearheaded the project. “People lived in isolation, cut off from family and denied their rights, but were still determined to carry on their lives,” she said. “We hope that everyone who walks into the story gallery will be inspired by their struggles.”



The story gallery is located within the settlement’s community hall, which was extended to accommodate the museum. The gallery complements a number of government-run galleries and there are plans to turn the settlement—known today as the National Leprosy Control Centre—into an open-air museum.

For more information: www.valleyofhope.my ■

FOR THE ELIMINATION OF LEPROSY

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FROM THE EDITOR

A SAD LOSS

As we were about to print this issue, we learned of the untimely death of Mr. Javed Abidi, the global chair of Disabled Peoples’ International—the endorsing organization of this year’s Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy.

Mr. Abidi (photo) acknowledged that the disability movement at large had neglected the cause of persons affected by leprosy and made it his business to help bring leprosy into mainstream disability discourse. “In my eyes, there is no difference between a blind person, a deaf person, a wheelchair user, and a person affected

by leprosy, Down’s syndrome, autism or any other disability,” he told this newsletter back in 2013. But at the same time, he urged the leprosy community to come “knocking on the door” and he put out the welcome mat.

“You have to be vocal; you have to fight for your own rights,” he said at the time. It was a message he repeated this January and is one we shall remember him by.

