THE
mission
TO END LEPROSY

www.tmtel.org

THE
mission
TO END LEPROSY

# End Leprosy:

## Join Us in Eradicating the World's Oldest Disease

Will You Protect Future Generations
from Needless Suffering?


Every 2 minutes, someone, somewhere, is diagnosed with leprosy. **That's nearly 250,000 people per year.**

**This year alone, about 50,000 children will hear the words, "You have leprosy."**

And there are tens of thousands more who will remain undiagnosed.

Over the past 20 years, between 12 and 15 million people have contracted leprosy but remain untreated.

If provided with the appropriate care, these individuals can live lives free of disability, isolation, and suffering.

**We need your support to raise $3 million for Phase 1 of the eradication program.**

**Can we count on your help?**

# A Message from the C.E.O.

Twenty years ago I had never met anyone who had leprosy. In my mind, leprosy was a Biblical disease. I honestly thought leprosy was dead and gone, confined to the pages of history.

Then I met a child named Dhukia.

Her young skin was mangled and gnarled. Her feet were wrapped in bandages. Her face was almost expressionless. Her father abandoned her, leaving her for dead.

It started when Dhukia lost all feeling in her feet – a common symptom of leprosy. She walked through thorns and over sharp rocks and felt no pain. Even when her feet bled, she ignored them. The local healer prescribed heat to cure the wounds. Every night, she rested her feet at the edge of the hot coals of the fire. Feeling no pain, she burned the soles of her feet severely. The damage was permanent.

Finally, Dhukia and her father walked for three days to the hospital. Her father told her he would be back in a week. Dhukia waited and watched for her father.

But he never returned.

I imagine her father prayed that the good people at the hospital would care for his little girl. I imagine he made that choice along the long walk, thinking of his three healthy daughters at home and the horrible stigma they would bear if he brought Dhukia back to their village.

He knew if he brought Dhukia back to the village, she would be tormented. Perhaps even beaten. The whole family would be stigmatized because Dhukia had leprosy.

So, he made a choice to save the rest of his family by abandoning Dhukia.

No parent should ever be forced to make this choice. No child should ever live with the painful reality of knowing she was abandoned.

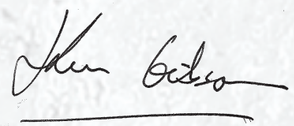
The day I met Dhukia changed my life. I became committed to the children, women, and men who continue to suffer from the age-old stigma of leprosy – even though it can be completely cured.

**Now is the time to end this suffering. Now is the time to rid the world of this ancient and cruel disease.**

You can be a part of this amazing effort. **You can say: "I played a part in ridding the world of leprosy!"**

I encourage you to keep reading – and consider how you can join the effort to end leprosy once and for all.

Sincerely,



Ken Gibson
C.E.O.
The Mission to End Leprosy

# Leprosy: The Disease

Leprosy is the world's oldest known communicable disease and is thought to have originated thousands of years ago. Leprosy once affected all of the world. Today it still lurks and lingers in the poorest communities of the world. The word "leper" has often been used as an insult to describe people who are outcast and feared. Although we no longer use this term, unfortunately, people with leprosy often continue to be despised and stigmatized. We believe it is an injustice that the cure now exists, but millions of people cannot access it because they are too poor.

**Here are a few facts about leprosy:**

- Every two minutes of every day, someone, somewhere, is diagnosed with leprosy.
- Also known as Hansen's disease, leprosy is a chronic infection passed through droplets in the air.
- The infection is caused by Mycobacterium leprae.
- The bacteria affect the nervous system, attacking the hands, feet, and face.
- Left untreated, leprosy causes life-long disability through ongoing ulcers, bone reabsorption, and tissue reduction.
- The stigma of leprosy is real and often casts people affected by the disease out of their community.
- Leprosy is curable. When diagnosed and cured in early stages, leprosy leaves no scars.
- The cure for leprosy, an antibiotic treatment, was discovered at Trinity College in Dublin, Ireland. It was first used to cure leprosy in the 1980s.

## The Mission to End Leprosy: Strategically positioned to lead eradication.

Operating from Ireland since 1874, we have a global track record and reputation as compassionate and effective leaders of change. Our experience, evidence-based learning, and faith prepare us to go forward. The significant engagement of partners and experts have led to our focus on ending leprosy. **Here is a brief history of our journey:**

1. **Breaking from tradition: 2011: The Global Fellowship Agreement between Leprosy Missions Worldwide.** Founded in Ireland in 1874, The Leprosy Mission grew to an international network spanning some 50 countries. The network continues to be coordinated by a secretariat in London. In 2011, The Mission to End Leprosy determined that its goal of eradication was better facilitated as an independent organization. Since then, it has built an agile global network that can deliver on the ultimate objective of the eradication of leprosy.


# Leprosy: I didn't know it still existed

You may have heard that the The World Health Organization (WHO) declared leprosy eliminated in the year 2000. That does not mean that it has been eradicated. It simply means that official statistics show that less than 1 in 10,000 people suffer from the disease. Without surveying for the disease, only people who present at a health care facility are diagnosed and treated. These are the only people represented in the statistics. Because leprosy is stigmatized in poor and remote areas, many people are afraid to or unable to access the care that they need. Left untreated, these people are condemned to lives of needless disability and suffering. They also remain a source of infection in their communities.

Over the past 20 years, up to 15 million people have been infected but have neither been diagnosed nor treated. Eradicating leprosy means zero new cases and no more suffering. We need your help to make that happen.

**Measuring the number of people affected by leprosy is fraught with challenges:**

1. Even within countries where "elimination has been achieved," there are regions that are saturated with high rates of new cases of leprosy. In 2017, WHO listed 22 Priority Countries where high endemic areas can be found. The statement seems ironic for a disease already declared eliminated.

2. Leprosy is a disease of the poor, most of whom do not have access to health care. People infected but untreated continue to spread the disease. Without an official diagnosis, these people do not contribute to the official numbers reported in a country or by WHO.

3. People affected by leprosy must present at a health care facility to be tested and diagnosed. In remote and poor regions, neither the health education nor the necessary resources are available. This increases the likelihood of developing a disability.

4. In the year 2000, the treatment period was decreased from 24 to 12 months. This has artificially reduced the number of active cases. Leprosy treatment depends on the intensity of the infection. While many cases can be treated in 12 months, not all can be. Without proper follow-up, patients return to their communities still carrying the infection.

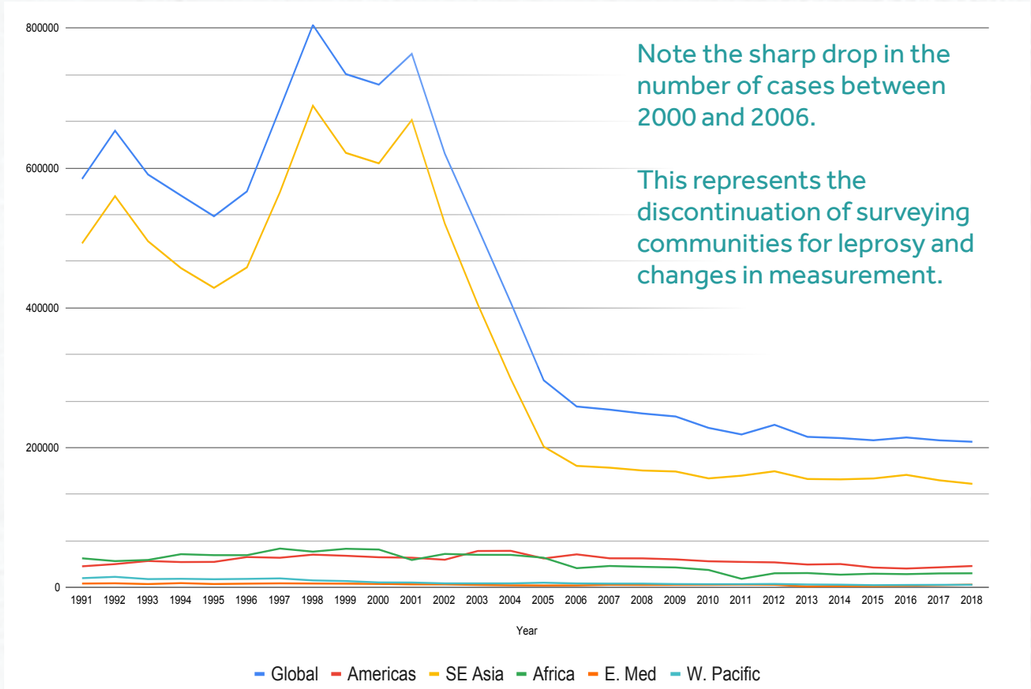
5. Changes in the definition of who has leprosy have reduced the number of cases annually - but only as a statistic, not in reality! Pre-1988 cases included people diagnosed, in treatment, needing medical assistance, and living with disabilities. Today it includes only people in treatment.

2. **2012: Strategic Plan.** Recognizing that the UN Millennium Development Goals Project was scheduled to end in 2015, the board adopted an interim strategy for 2012-15 entitled "gearing up for a world beyond 2015." The priority was "to work at all levels of society to effect sustainable transformation with and on behalf of people and communities affected by leprosy." A key feature of the strategy was to work in cooperation with partners and donors. **This became the birthing ground of the organization's Global Advocacy Plan, which was formulated in 2013.**

3. **2013: Global Advocacy Plan formulated.** The organization formulated a plan and program to influence policy and practice at WHO. We were delighted to see that all of our objectives were reflected in WHO's 2016-20 leprosy strategy.

# Leprosy: Solving the problem

Registered Cases, Global and by Region: 1985-2018 (Source: WHO WER)




Note the sharp drop in the number of cases between 2000 and 2006.

This represents the discontinuation of surveying communities for leprosy and changes in measurement.

## When campaigns to detect leprosy are organized in regions that are known to have leprosy, we see a sharp rise in cases.

The graph shows that when cases of leprosy were looked for through detection campaigns (between 1991 and 2000), high numbers of cases were detected, peaking at 800, 000.

The number of new cases has fallen to between 200, 000 and 250, 000 per year since the year 2000. This drop in new cases has nothing to do with the prevalence of the disease decreasing but is brought about because there is no active case surveillance.

# Leprosy: So much more than a disease

Leprosy affects people, their families, and communities physically, mentally, socially, economically, and spiritually.

Leprosy denies people:

- Basic human rights
- Economic wellbeing
- Access to education
- Inclusion in society
- Gender equity

### The Missing Millions:

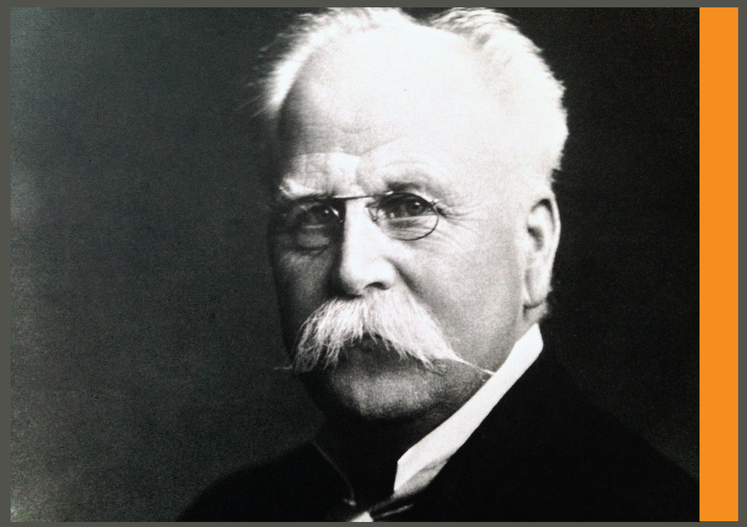
**More than 600,000 people per year who would otherwise have been diagnosed by active case detection are now not being detected.** Over a 20-year period, this equates to 12 million people. Undetected and untreated, they remain a source of infection and transmission. They also face a future of needless disability.

### Key to breaking transmission:

Only one-third of the cases are reported voluntarily. **Awareness of leprosy is not adequate to motivate the patients to report voluntarily** and complete their treatment, thus underscoring the need for relying on active case detection so that transmission can be broken and elimination of leprosy achieved. In addition, the influence of socioeconomic factors on continued occurrence of leprosy cannot be ruled out.

**4. 2014: Theory of Change consultations.** Jointly funded by effect:hope and The Mission to End Leprosy, theory of change consultations were held in Addis Ababa, Ethiopia. The two funding partners listened carefully to representatives of implementing (field) partners from across Asia and Africa. The lessons learned from these consultations influenced the post-2015 strategy. These discussions brought a new depth of understanding to our work, making it easier to design, develop, and maximize the impact of our programs.

**5. 2014: Delivering The Promise Conference.** We hosted a conference in Dublin to critically explore WHO definitions, policies, and practices and to move towards a consensus on WHO's 1991 commitment to eliminate leprosy. The conference was attended by academics, practicioners, heads of Non Governmental Agencies, and members of WHO committees. The conference mandated The Mission to End Leprosy as an advocate for change in WHO policy. Using our networking and influencing skills, we subsequently worked to have the key output of that conference reflected in global policy.



# Who We Are

Our founder Wellesley Bailey was a man of vision, faith, and compassion. His very first encounter with men and women affected by leprosy shattered him.

Long before the cure was discovered, Wellesley saw beyond the disease to the person hiding behind the dreadful disability.

It was Christian compassion that first inspired Wellesley Bailey in 1874. Today, we continue to celebrate the Christian values and principles that define and shape our work: honor, dignity, justice, and inclusion. In living out these principles, we strive to be honest, open, and transparent.

We deliver our services without question of race, gender, sexual orientation, religion, philosophy, worldview, or any other classification that others often use to divide and segregate. The bedrock of our approach is the Christian understanding of the equal value of every human being.

The Pim sisters of Monkstown, Co. Dublin, inspired the Irish commitment to serving people affected by leprosy. Their first charitable gift of £30 in the mid 1870s has multiplied into millions of lives restored.

6. **2014: Symposium: Developing Strategies to Block the Transmission of Leprosy.** In Houston, Texas, we participated in a symposium funded by effect:hope. Scientists from all continents gathered to clarify the current state of knowledge regarding *Mycobacterium leprae* and to identify and address gaps in our understanding of transmission. This has been instrumental in giving a global voice to our shared agenda on scientific research into transmission and eradication.

7. **2014: Strategic Plan for beyond 2015.** Arising from the Theory of Change discussions in Ethiopia, a new strategy was developed and focused on the following four key areas: **1: Advocacy:** Ensuring those with power play their part, **2: Health Systems:** Supporting and strengthening local systems, **3: Communities:** Equipping and strengthening communities to be leaders of change, **4: Research:** Asking important questions to move towards eradication of leprosy.

# The plan to eradicate leprosy

PHASE 1:
## Building the Model

Working with communities in Africa, Asia, and Latin America, we will prove that leprosy can be eliminated over a 5-year period.

PHASE 2:
## Global Rollout

Using the data collected and models developed in Phase 1, we will implement the learnings in all regions where leprosy exists.

## **GOAL:** Eradicate leprosy worldwide

### STRATEGIES OF THE PROJECT

- Reduce infection rates through early detection and treatment
- Ensure compliance with treatment
- Protect high risk groups
- Increase access to health care to prevent disease

### OBJECTIVES

- Detect all new cases of leprosy in the defined communities
- Ensure compliance of treatment in all patients who are on Multi Drug Therapy (MDT)
- Trace household and other contacts of index leprosy patients, and administer chemoprophylaxis

### METHODOLOGY

In four leprosy endemic countries, across three continents, eight communities will be selected. Total population in Phase 1, across these site will be approximately 1 million people.

The activities will be carried out by using Community Volunteers selected from the populations that are chosen. The activities will be monitored by a supervisor. Both the Community Volunteer and the Supervisor will work closely with the local government health staff who are implementing the leprosy program. The Community Volunteer and the Supervisor will collect and maintain data for the project.

### LOCATIONS OF PHASE 1


8. **2015: R2STOP.** R2STOP, **Research to Stop Transmission of leprosy and neglected tropical diseases** was launched. This scientific research initiative, jointly funded by Effect:Hope and The Mission to End Leprosy, with an expected budget of $1 million per year launched. In 2016, the first call for proposals saw just over $1 million awarded across six research projects all of which focused on understanding and stopping the transmission of leprosy.

9. **2016: The Missing Millions Conference.** We called and hosted a conference in Dublin that was attended by heads of government health departments, program managers, and people affected by leprosy from across Africa, Asia and Latin America. One of the main purposes of the conference was to explore opportunities offered by the new WHO Leprosy Strategy 2016-2020 to address the "missing millions." These "missing millions" are the people affected by leprosy and its consequences but who are not being effectively diagnosed, treated, or supported. The Mission to End Leprosy received a clear mandate to continue this work as a global advocate.

## ACTIVITIES

Over a five-year period, the specific communities will be involved with:

**a) Early case detection:** Community Volunteers will be involved in carrying out door-to-door surveys in examining the entire defined population to detect cases of leprosy. The surveys will be done at the beginning of the project, third year and at the end of the fifth year.

**b) Treatment:** Trained Community Volunteers ensure all patients who are on MDT will complete treatment within the prescribed time. Community Volunteers will carry out contact examinations and administer chemoprophylaxis to close family members to deter infections as per the guidelines of the global or government leprosy program.

**c) Vaccination:** Community Volunteers will advocate for and encourage Bacille Calmette-Guérin (BCG) vaccination among children.

## OUTCOME MEASURES

**Baseline Data**

At the beginning of the project, baseline data related to the demographic details of each site will be captured through the first door-to-door survey.

**Annual New Case Detection Rate (ANCDR) =**

# new cases / population of 100 000

**Compliance Rate for MDT =**

Percentage of patients who completed MDT within the prescribed time

**BCG Coverage**

Secondary data

a) Prevalence rates,
b) Multibacillary proportion,
c) Child rate,
d) Grade 2 disability rate among new cases,
e) Grade 2 disability among children and relapses

**Contact Tracing and Chemoprophylaxis Coverage =**

a) Percentage of enumerated contacts traced and examined
b) Percentage of new cases identified during contact tracing
c) Percentage of chemoprophylaxis given to eligible contacts
d) Percentage of contacts who received chemoprophylaxis and developed leprosy
e) Percentage of contacts who refused chemoprophylaxis and developed leprosy


**10. 2016: Reflection on WHO Strategy.** Reflecting on the new WHO Strategy, we noted that while we welcome the strategy and its focus on zero disease, zero disability, zero transmission and zero discrimination, we do not believe that it will deliver as it fails to address the core underlying structural and procedural issues. This drove us back to consider, "What would it take to eradicate leprosy?" To answer this, we formulated the current program.

**11. 2016: The Mission To End Leprosy.** While retaining the legal names of The Leprosy Mission Ireland and The Leprosy Mission International, the board adopted the trading name "The Mission To End Leprosy." The Mission to End Leprosy committed to registering in USA, UK, and India. The adoption of this name clearly confirms the board's commitment to eradication.

*I salute the unwavering dedication and commitment of The Mission to End Leprosy. You are a wonderful example of a caring spirit and what can be done when people pool their energy and ideas to make life more humanly decent for others. I am very glad to have this opportunity to acknowledge the contribution you have made to the lives of the victims of this most distressing condition. Through your efforts, you have assisted many sufferers to live full, independent, and satisfying lives.*

**MARY MCALEESE**
Former President of Ireland and
The Mission to End Leprosy Patron

## ASSUMPTIONS:

- The personnel of government leprosy programs have the requisite skills to accurately diagnose and effectively treat leprosy
- MDT supply chain is functional and uninterrupted
- The social contacts of index cases will be willing to accept chemoprophylaxis
- All human foci and reservoirs of M. Leprae will be identified and dealt with as a large population is targeted in a defined geographical location
- Extra human reservoirs of M Leprae have no major role in transmission
- Present chemoprophylaxis is effective in rendering an exposed and infected contact bacteriologically sterile to prevent transmission
- Present MDT is effective in killing all the viable bacilli in highly bacilliferous patients preventing further transmission
- Migration of population into and out of the chosen geographical area is minimal

## RISKS AND MITIGATION

- The coverage of door-to-door survey is optimal where all enumerated persons are examined for leprosy

  *The family card system will be used for gathering the data during door-to-door surveys. This family card will enumerate all the members of a family. The elder of the family can confirm that each enumerated member has been examined. Supervisors can do random checks and monitoring.*

- MDT is being regulated with all daily doses consumed

  *Regular MDT blister pack examination for tablet count by the Community Volunteers and one of the family members will ensure intake of tablets as prescribed.*

- A large proportion of social contacts may refuse chemoprophylaxis as no one in their families is affected

  *Proper health education can be given to motivate and convince social contacts to take chemoprophylaxis.*

- Retention of well-trained Community Volunteers and Supervisors under the project

  *Frequent motivation and strengthening commitment among project staff towards project completion and impressing upon them the importance of this evidence in the eradication of leprosy.*

- The reduced priority of leprosy programs among local and national governments (especially when governments and key personnel change) may affect the running of the project

  *The project will have to adapt and make the requisite changes to keep up the activities and momentum.*

- The rate of drive down of ANCDR (the primary outcome measure) may not be significant as anticipated

  *If the anticipated or significant drive down of ANCDR (Annual New Case Detection Rate) does not happen, the evidence is vital in assuming the present interventions are not sufficient and thought may be given to what further needs to be done.*

## RESEARCH

Data produced in Phase 1 will include:

- Effectiveness of Single Dose Rifampicin for chemopophylaxis
- Effectiveness of MDT in highly bacilliferous patients
- Transmission links in a given community
- Occurrence of leprosy among contacts
- Relationship between delay in diagnosis and development of severe disease and disability
- Disability rates in the chosen population over five years
- Effectiveness of chemoprophylaxis in preventing the disease

**12. 2017: Review and Exploration.** Throughout 2017, we revisited our burning question: "What would it take to eradicate leprosy?" After extensive discussions, our board restated its commitment to eradicate the disease, and a period of research and reflection informed the design of a model for the eradication of leprosy.

# How You Can Help

With your help, The Mission to End Leprosy can eradicate the world's oldest disease forever.

### Return on Investment

Your gift will help us provide health screenings, leprosy detection, and treatment for a population of one million people every year over a five-year period.

By giving to the eradication campaign, you will save lives today, tomorrow, and for generations to come.

### Thank You to Our Donors

Because of our generous donors, The Mission to End Leprosy has been changing lives for 140 years. Thank you for your years of dedicated support. It's because of you that we have arrived at this important moment.

### Your Gift

Please consider making a gift to end leprosy.

Our goal is to raise $3 million for Phase 1 of the eradication program.

Gifts of appreciated stock, gifts from Donor-Advised Funds, IRA distributions, and all planned gifts are welcome. Please let us know if your workplace matches your gift.

Please make your gift out to The Mission to End Leprosy, 708 3rd Avenue, Floor 6, New York, New York 10017.

## WHAT WE NEED TO RAISE

| Gift Range | # of Gifts Required |
|---|---|
| $500,000 | 1 |
| $250,000 | 3 |
| $150,000 | 3 |
| $100,000 | 4 |
| $50,000 | 6 |
| $25,000 | 8 |
| $15,000 | 10 |
| $10,000 | 15 |
| $5,000 | 15 |
| $2,500 | 15 |
| Total | 80 |

# Leaders

Ambassador:
**Enda Kenny, Former Prime Minister of Ireland**

Vision, Strategy, and Relationship Management:
**Ken Gibson**

Program Development and Implementation:
**Dr. Mannam Ebenezer**