Action on Neglected Tropical Diseases in India
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Global Health Progress (GHP) is a collaborative initiative funded by research-based biopharmaceutical companies. GHP is committed to finding sustainable health care solutions for the developing world by joining forces with public health leaders, foundations, governments and others. GHP provides a platform that marshals the collective expertise and resources of biopharmaceutical research companies to find solutions to access to healthcare by:

• Promoting sustainable approaches to improving access to medicines in developing countries;
• Developing innovative tools, medicines and mechanisms to fight neglected diseases; and
• Raising awareness of global health challenges and current efforts to improve health.

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Foreword

By Mr. Anshu Prakash,
Joint Secretary, Ministry of Health & Family Welfare, Government of India

FOREWORD

The stakeholders meeting organized in New Delhi in September, 2013 on “Partnering for Success – Reducing India’s Burden of Neglected Tropical Diseases” was an excellent initiative which brought together policy makers, civil society, implementing agencies, pharmaceutical companies and the media on a common platform. The meeting was successful in focusing attention on these diseases afflicting the poor and marginalized communities in India and other Asian and African countries. The very name, “Neglected Tropical Diseases”, is an admission that these diseases are considered neglected and therefore deserve high attention. We all need to work together so that the world can be rid of these diseases.

India has supported the London Declaration of 2012 and has joined other member nations at the World Health Assembly this year to adopt a resolution for controlling, eliminating and eradicating 17 identified Neglected Tropical Diseases. The Indian Government is working with all stakeholders and the community towards meeting these objectives. Given the size and population of India, the action taken by us will certainly impact the global figures. We are committed for a sustained momentum in our efforts.

The stakeholders meeting in New Delhi and the subsequent report made available will certainly facilitate the chalking out of strategies and for the future course of action. We hope that with the combined efforts of all stakeholders the Neglected Tropical Diseases would vanish from the face of this earth.

I congratulate the Organizers for conceiving the idea and successfully holding this meeting.
India is uniquely positioned to lead the global fight against Neglected Tropical Diseases (NTDs). As well as shouldering a large disease burden, new multi-stakeholder partnerships are successfully leveraging political and economic support towards investment for research and development, to treat and prevent NTDs.

Held on 9 September 2013, the New Delhi meeting of experts on NTDs: “Partnering for Success – Reducing India's Burden of Neglected Tropical Diseases” represents a new, strategic drive to accelerate progress toward controlling, eliminating and ultimately eradicating NTDs in India. The meeting, and this subsequent report, is a global milestone that builds on the success of the London Declaration 2012 and the World Health Assembly resolution on NTDs made earlier this year.

Partnerships between the Government of India, pharmaceutical companies, donors, health professionals and civil society have contributed technical knowledge, drugs and research funding for NTDs in India. Recognising that there has been immense progress in tackling NTDs, we must work together to build on public health successes, like the eradication of yaws and polio from India. We must also expand and extend drug access programmes to ensure the necessary supply of drugs and other interventions to help control and eliminate diseases like soil-transmitted helminthes, Chagas disease and visceral leishmaniasis.

Pharmaceutical companies are already doing a lot to prevent and treat NTDs in India and it will be crucial to provide ongoing incentives to ensure the production of new tools for the market. We must support R&D through partnerships and provision of funding to find next generation treatments and interventions for neglected diseases. Improved diagnostics must be a priority so that we can better understand the true burden of disease and the careful monitoring and evaluation of NTD programmes will be critical so that we can identify the bottlenecks to success and develop multi-stakeholder strategies to overcome these challenges.

For India to achieve its ambitious NTD goals, we must also work with other sectors to ensure that communities have access to clean water and sanitation, improved living conditions, vector control, and stronger health systems in endemic areas.

There is a moral imperative to control, eliminate and eradicate NTDs from India and the world. The Organisation of Pharmaceutical Producers of India stands ready to work with all stakeholders to ensure that real progress is made and the poorest communities get access to new prevention and treatment tools.

Foreword

By Ms. Ranjana Smetacek,
Director General, Organisation of Pharmaceutical Producers of India
India has the highest burden of NTDs in the world, which disproportionally affect those from the poorest and most marginalised communities and locks people into a cycle of poverty and disease. Stakeholders agree that there is a joint moral obligation to prevent, control, eliminate and ultimately eradicate NTDs in India (and globally). Strong multi-stakeholder partnerships will be the critical element to fully understanding the burden of disease, increasing R&D, integrating approaches and building political and economic will for NTD interventions.

There are many examples of what is possible when government, academia, industry, civil society, donors and patients come together and commit resources, both human and financial. NTDs can be controlled and eliminated – even eradicated – but we need to find a mixture of incentives to unite stakeholders. Companies need incentives to produce new products for the market and the public needs to understand the scale of the NTD challenge and this can be enhanced by greater media coverage.

Ultimately, political leaders must be held accountable for successes and failures in controlling and eliminating NTDs. The timely gathering of experts in New Delhi, which builds on the WHO 2020 Roadmap, the London Declaration on NTDs and the 2013 World Health Assembly resolution on NTDs, emphasised the need for a comprehensive approach to tackling NTDs.

Diseases like leprosy highlight the medical, public health and social challenges to NTDs and we must simultaneously act on all fronts.

Furthermore, we must ensure a coordinated approach to surveillance, prevention, and treatment to improve our efforts to control and eliminate NTDs. Yaws and polio provide a roadmap for how we can reach the poorest and most marginalised communities with lifesaving drugs and treatment. To ensure that further products are available so we can replicate these successes, a strategic research agenda spanning basic, translational, and operational research is needed to streamline effective research and development.

As India continues to grow and develop, providing health services to the poorest and most marginalised will be a critical indicator for whether India’s growth is actually inclusive and benefiting the whole country. With the Government of India taking the leadership role, cooperating closely with other sectors, the ultimate success will be measured by the collective ability of stakeholders to tackle NTDs. Regular monitoring and evaluation will ensure that progress is built upon and challenges are overcome.

NTDs can be controlled and eliminated. The stakes are high, and the lives and futures of millions of people depend on the decisions and actions we take in the coming months and years.
The neglected tropical diseases are a diverse set of bacterial, viral, and parasitic pathogens that collectively cause significant illness and debilitation, primarily in impoverished communities of low and middle-income countries. Traditionally, these diseases have been overlooked or under-resourced compared to other higher-mortality diseases and, as a result, afflicted patients have been under-diagnosed and under-treated. The term “Neglected Tropical Diseases” (NTDs) was coined to galvanise support and funding around these illnesses. The World Health Organisation (WHO) has grouped 17 diseases under the NTD banner (Table 1: The WHO list of recognised NTDs) that collectively affect over one billion people worldwide and are endemic in 149 countries.

Over the past few years, the interest and commitment of the international community in addressing NTDs has grown. Largely catalysed by the WHO’s 2020 Roadmap on NTDs, the 2012 London Declaration and most recently the 2013 World Health Assembly resolution addressing all 17 NTDs, India and other countries have accelerated efforts to address these important tropical diseases. The Government of India has shown significant leadership in addressing NTDs, including the elimination of yaws and leprosy and most recently launching the world’s largest de-worming campaigns targeting soil-transmitted helminth (STH) infections in children and adolescents. Despite this progress and increased commitment, several challenges remain, including: understanding the full burden of NTDs in the country; reaching the poorest and most marginalised populations with quality tools and services; increasing research and development for NTDs; applying best practices and integrating services; and, building and sustaining political and economic support.

On 9 September 2013, leaders from the government, academia, research, industry, NGOs and donors came together at “Partnering for Success – Reducing India’s Burden of Neglected Diseases” to discuss critical NTD challenges in India.
Associations (IFPMA) and the Organisation of Pharmaceutical Producers of India (OPPI), and supported by Global Health Strategies, the meeting aimed to share best practices and challenges, highlight progress to date and the way forward to achieve the control and elimination of NTDs in India. The following report draws heavily from these discussions.

London Declaration on NTDs
In January 2012, an international coalition of pharmaceutical companies, non-governmental organisations (NGOs) and governments pledged to control or eliminate 10 NTDs by 2020 in line with targets set by the WHO. These commitments, captured in the landmark London Declaration on Neglected Tropical Diseases, represented the largest coordinated action to date to address the burden of NTDs. Of the ten NTDs included in the London Declaration, the diseases that are most prevalent in India include lymphatic filariasis, soil transmitted helminthiases (STH), trachoma, leprosy and visceral leishmaniasis. Other NTDs not included in the London Declaration but of a high burden in the country include dengue, rabies, cysticercosis and Japanese encephalitis.¹

¹Japanese encephalitis is not classified as an NTD by the WHO but still an important tropical disease in India.
Understanding the Burden of Neglected Tropical Diseases

Despite tremendous advances in the health of its poorest citizens, India bears a disproportionately high burden of NTDs, with over half of the 17 WHO classified NTDs at endemic levels. It is estimated that nearly 290 million people are infected, and that a significant proportion of those afflicted, especially children, may be simultaneously infected with more than one NTD. In addition to making life extremely difficult for many of India’s poorest populations, such a tremendous disease burden has a doubly lethal affect by causing huge economic losses in a population that already lives on less than US $2 dollars a day.

The exact NTD burden in India is not fully known. Limited studies have been conducted and in 2011 a meta-analysis using previously published data on India and global mapping studies to estimate the prevalence of the major NTDs (Table 2: NTD burden in India). In order to truly understand the impact of these diseases on the subcontinent, major large-scale epidemiological mapping and surveillance are needed.

Many NTDs lack point-of-care diagnostic tools and require laboratory-intensive methods to definitively diagnose. Increasing R&D for innovative diagnostic tools is essential to improve understanding of the full NTD burden. Furthermore, strengthening existing surveillance programmes will not only help facilitate understanding the true incidence and prevalence of NTDs but can help NTD control and treatment programmes to effectively reach high burden areas.

Dr. C.P. Thakur
Member of Parliament, Former Union Health Minister, Government of India & Chairman, Balaji Uthan Sansthan, Kala-azar Research Centre

“Kala-azar can be eliminated. It requires the will of the government and the will of educated partners and helpers.”
TABLE 1: List of 17 NTDs as classified by the World Health Organisation

- Buruli Ulcer (Mycobacterium ulcerans infection)
- Chagas disease
- Dengue/Severe dengue
- Dracunculiasis (guinea-worm disease)
- Echinococcosis
- Foodborne trematodiases
- Human African trypanosomiasis (Sleeping sickness)
- Leishmaniasis
- Leprosy
- Lymphatic filariasis
- Onchocerciasis (River blindness)
- Rabies
- Schistosomiasis
- Soil transmitted helminthiases
- Taeniasis/Cysticercosis
- Trachoma
- Yaws (Endemic treponematoses)

2http://www.who.int/neglected_diseases/diseases/en/

TABLE 2: Burden of Leading NTDs in India

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number of Cases</th>
<th>Percentage of Global Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ascariasis*</td>
<td>140 million</td>
<td>17%</td>
</tr>
<tr>
<td>Trichuriasis*</td>
<td>73 million</td>
<td>12%</td>
</tr>
<tr>
<td>Hookworm infection*</td>
<td>71 million</td>
<td>12%</td>
</tr>
<tr>
<td>Lymphatic filariasis</td>
<td>6 million</td>
<td>5% (based on 0.53% prevalence)</td>
</tr>
<tr>
<td>Tracoma</td>
<td>1 million</td>
<td>1-2%</td>
</tr>
<tr>
<td>Visceral leishmaniasis</td>
<td>Not determined</td>
<td>Not determined</td>
</tr>
<tr>
<td>Leprosy</td>
<td>87,190 registered cases</td>
<td>41%</td>
</tr>
<tr>
<td>Rabies</td>
<td>20,000 cases/deaths</td>
<td>36%</td>
</tr>
<tr>
<td>Japanese encephalitis</td>
<td>1,500-4,000 (incidence)</td>
<td>Not determined</td>
</tr>
<tr>
<td>Dengue</td>
<td>Not determined</td>
<td>Not determined</td>
</tr>
</tbody>
</table>

*Ascariasis, Trichuriasis and Hookworm infections are the three soil-transmitted Helminths

3http://www.who.int/neglected_diseases/diseases/en/

Visceral Leishmaniasis (Kala-azar)

India accounts for a large share of the global burden of visceral leishmaniasis or kala-azar, which has routinely re-emerged from near elimination in the country. The disease is spread by the bite of a sandfly and is fatal if not treated. Spraying of residual insecticide has at times lowered the number of cases, however outbreaks have continued over the past decades and cases have remained in the tens of thousands.

Although kala-azar patients often arrive at health centres before they have reached the acute stages of the disease, due to a lack of rapid diagnostic tests and improper training of medical staff, the disease is often missed. This can have deadly consequences. Growing drug-resistance is a major challenge and the development of a vaccine would be the most effective solution in limiting deaths.

New partnerships are aiming to make inroads in controlling the disease. A collaboration between Dr. Prathip Das at the Rajendra Memorial Research Institute of Medical Sciences in Patna and the Liverpool School of Tropical Medicine (LSTM) has led to dramatic improvements in the way we control the sandfly vector that causes kala-azar. Traditionally, Dr. Das’ team would have to engage in resource-intensive, laboratory-based tests to determine if the levels of pesticides being used were adequate to kill the sandfly. These tests took two days to return, by which time spraying teams would often have moved onto a new area and unable to circle back and respray if needed. Through a Wellcome Trust grant, a group at the LSTM developed a point-of-care test that allows realtime detection of pesticide levels, thus allowing repeat spraying if needed.

Dr. Dipika Sur
National Institute of Cholera and Enteric Diseases

“Most of these diseases have high prevalence in localised areas and our estimates of disease burden are wholly inadequate due to the lack of actual data that exists.”
A key challenge to reducing India’s massive burden of NTDs is to reach the poorest and most marginalised communities, which are disproportionately affected by these diseases. Yet, the eradication of yaws and polio in India demonstrate that all communities can be reached with critical health services and interventions.

**Bridging the Gap**

The fact that NTDs are mainly diseases of the poorest and most marginalised communities is a challenge in itself. Polio showed that all communities in India could be reached. However, the lack of market incentives involved with reaching those affected by NTDs has had a negative effect on the investment and human resources put toward discovering new vaccines and drugs.

With out-of-pocket-expenses representing 75 percent of all expenditure on health, seeking treatment for NTDs can lead to families falling into poverty (or further poverty). The threat of poverty leads to families delaying accessing health services and only seeking care when the disease has become advanced. This usually increases both the amount of care (and hence money) needed for the patient to recover and also the likelihood of a victim becoming infected by other NTDs and diseases.

All stakeholders need to urgently focus on eliminating NTDs. Increased resource allocation is needed based on the moral imperative to help the poorest and most marginalised escape the cyclical problem of NTDs and its direct correlation with poverty.

**Importance of Local Leadership and Community Involvement**

While leadership and direction for policies and programme from the central government is important, equally vital is state- and district-level leadership and ownership to adapt programmes and policies to fit local contexts and needs, and to ensure that communities have access to vital tools and services. Many interventions are successful in one particular state or region but do not perform as well in another. Local ownership is critical to contextualise an intervention or programme to a particular region. Community mobilisation can raise awareness and generate demand and community
involvement and acceptance is often the key to success, particularly with regards to interventions aimed at addressing a social or cultural aspect, changing norms or providing health education for behaviour change. Leprosy programmes, for example, require not only providing treatment and care, but also have to take into account deep seated social stigma and misconceptions linked to the disease. Bringing the community into the planning stage of prevention and treatment, and partnering with them throughout all stages, helps increases the likelihood that interventions are effective.

Ultimately, the Government of India must lead and be accountable for progress on NTDs. Companies need to be assured of a sustainable market for their product. Increased media attention on these diseases would help raise awareness and give the public reason to engage.

**Successful Polio Eradication in India**

A polio free India was once described by experts as impossible. However, in 2012, the WHO removed India from the list of polio endemic countries after completing one year without a single case of polio. India is now nearing its three year milestone in January 2014, which will lead to the WHO officially declaring India, polio free. This will mark one of the greatest global public health achievements of all time.

In 2009, India had more cases of polio than anywhere else in the world. But political commitment at the centre, state and local levels, along with a national polio oversight body, helped identify and address challenges quickly and effectively. A partnership between the Indian government, the WHO, Unicef, Rotary International and the Bill & Melinda Gates Foundation raised more than US $2 billion and an army of two million vaccinators was deployed to reach more than 170 million children in polio immunisation campaigns each year.

New technological innovations like genetic sequencing helped to quickly identify where an outbreak of the virus originated, enabling field workers to rapidly stop it from spreading. A system to track newborn babies helped health workers reach them with the vaccine and other lifesaving interventions. Furthermore, celebrities like the actor Amitabh Bachchan pushed the message of polio eradication to the general public, and partnerships with religious groups helped break down scare stories and myths about the disease.

For NTDs, polio eradication offers more than just hope. Successful eradication provides both a model of public-private partnership and a roadmap for reaching the poorest and most marginalised communities across India. The monitoring system has already been used to reduce measles and could be used to effectively track, control and eradicate diseases like visceral leishmaniasis and other NTDs.
Leprosy Care in India

Leprosy is one of the oldest diseases known to mankind. With an estimated 58 percent of the global burden, India recorded 83,000 cases in 2011 and 127,000 new cases in 2012. Leprosy is addressed via the National Leprosy Eradication Programme, and India achieved elimination status in 2005. Still, leprosy remains endemic in several pockets throughout the country and in 2012 the country launched a special action plan to intensify efforts in 209 endemic districts. Leprosy services have also been integrated into general health services, including Primary Health Centres, ending the previously vertical approach.

A highly infectious and debilitating disease, leprosy can be severely disfiguring. For centuries, leprosy was incurable and those afflicted often lived in isolation and outcast from their communities. Since the 1980s, however, leprosy has been treated and cured using a multi-drug therapy (MDT) combination, which is curative against all types of leprosy and recommended by the WHO leprosy elimination strategy.

Despite these advances, low awareness of the disease, significant social stigma often tied to the disfiguring effect of the disease, and barriers to treatment and care are still prevalent. Efforts to overcome these challenges and provide rehabilitating care are needed as part of a comprehensive approach to addressing the disease. One notable model of this approach is the Novartis Comprehensive Leprosy Care Association (NCLCA).

The NCLCA provides free access to MDT, focuses on early diagnosis for the prevention of disabilities and rehabilitation services for those with disabilities or deformities, including physiotherapy, use of splints and corrective surgeries. They also aim to help former patients become more independent and integrated into society, including provision of self-care kits, which reduce the time and expenses associated with coming for treatment, and provision of resources for economic rehabilitation, which allow patients to contribute to the economic support of themselves and their families. NCLCA partners with the government and other NGOs to provide training services and distribution of self-care kits; the government has distributed over 48,000 self-care kits to date. The programme has been widely recognised as a successful model, including for its use of research, innovation and holistic approach toward the human face of leprosy.

Dr. Atul Shah, Novartis Comprehensive Leprosy Care Association noted: “Our work is an example of empowering patients in self-care and teaching them directly. This is one aspect that can be useful in addressing other NTDs, such as lymphatic filariasis.”

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Dr. Ratna Devi
Daksham A Health & Education

“I could have reached many more if I had understood what people wanted and how they wanted it, in what context they wanted it, and why they wanted it. Successful programmes are about providing informed choices and making implementation flexible enough to manage those choices.”
India’s Role in Research and Development for NTDs

**Overview**
Through a unique array of public-private partnerships and international funding that support interdisciplinary teams, significant advances have been made to diagnose, treat, and control these devastating illnesses. Importantly, there is also a growing interest in addressing the significant disease burden afforded by NTDs through the R&D of new diagnostics, vaccines, treatments, and control measures.

**Domestic Leadership**
India is becoming a major global player in R&D in the NTD field by increasing resources allocated to researching NTD pathogens. This has led to India currently out-producing several, major research nations including Japan, Germany and France.

**Current Gaps in R&D for NTDs**
Despite the growing interest in NTDs among the Indian research community, there remain many gaps in our understanding of these pathogens.
In addition to scant epidemiological data, there has not been enough translation of basic research into new technologies that could be applied in the field. All neglected diseases suffer from a dearth of point-of-care diagnostics, which undermines the ability to conduct the much-needed epidemiological mapping.

Even when diagnostics do exist, they are sometimes less applicable in the Indian context due to the strain variation that exists between where the tests are developed and the strains circulating on Indian subcontinent. There is an urgent need

**Dr. Shirshendu Mukherjee**
Wellcome Trust

“We need interdisciplinary and collaborative work to tackle the many research gaps that exist in the NTD field.”
to develop indigenous tests that account for the pathogen strains that are most locally prevalent.

While there are some treatments and control measures for the 17 NTDs, there are significant treatment gaps, especially for viral and bacterial pathogens. India has an especially high burden of viral NTDs such as dengue, and there is an urgent need to develop effective treatments and prevention measures for these illnesses. However, even when effective technologies exist to battle a particular disease, there are many barriers to implementing these discoveries in the field.

**Dr. M.M. Gore**
National Institute of Virology, Indian Council of Medical Research

“We need to move towards syndromic diagnostic kits that simultaneously test for multiple causes of a particular condition. These would be a more cost effective solution than individual disease-based tests.”

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**Vaccines for NTDs**

Vaccines are one of the most cost-effective preventive health interventions, yet they are largely unavailable for the 17 NTDs. For example, both a pre-exposure and post-exposure prophylaxis vaccine for rabies exists, although access and affordability to these vaccines remains a challenge throughout India.

A vaccine against dengue is rapidly becoming a reality and several companies have dengue vaccine candidates under clinical development or are initiating discovery programmes. Sanofi is anticipated to launch a vaccine in 2015, with tiered pricing options for wealthy, middle- and lower-income countries. The Serum Institute of India, in collaboration with the University of Mahidol in Thailand, recently announced a partnership to develop a dengue vaccine, and a similar partnership has been announced by a Malaysian company to partner with Russian institutes. Dengue, which primarily affects those in urban centres in India, is on the radar of policy makers due to increased media attention and awareness raising campaigns.

Vaccine candidates for other NTDs are less advanced and have fewer players involved. The primary drivers of vaccine R&D for NTDs are product development partnerships (PDPs). One such NTD PDP, the Sabin Vaccine Institute, is developing vaccines for Hookworm infections (phase 1 clinical trials), Shisitosomiasis (early development stages), Chagas disease (therapeutic vaccine) and leishmaniasis (early pre-clinical stages). Sabin also recently announced the launch of a STH vaccine discovery programme.
Fostering R&D in India

Given the huge research potential in India coupled with its significant disease burden, India has the potential to transform the landscape and trajectory of the NTD field.

Fostering interdisciplinary and inter-sector partnerships will also accelerate the transformation of academic research into new technologies. Academic scientists with disease expertise and industry leaders who are able to think about implementation and scalability of new technologies must synergise their relative strengths to transform the way we diagnose and treat NTDs.

In order to know how best to tackle the diverse set of diseases that comprise the NTDs, it will be critical to map the current landscape of R&D for each of the individual diseases. Armed with this information, the government, academia and industry, along with other partners, could together develop a strategic research agenda that begins to address gaps in NTD R&D in India.

Resources for R&D

Funding for R&D can prove challenging and incentives for companies to invest in NTDs are often low. Mechanisms that help overcome this include research into drug repurposement and risk sharing strategies, such as Product Development Partnerships. Open-source platforms are another way of overcoming lack of incentives to develop new and inexpensive drugs to combat diseases that disproportionally affect the poor. By opening a project to external contributors, research capacity may increase significantly. The Open Source Drug Discovery (OSDD) platform of the Council of Scientific and Industrial Research (CSIR) of India, is part of a global network of OSDD groups, and includes R&D projects for NTDs. The Government of India has also worked to catalyse R&D for health and agriculture in the Indian biotech sector by launching the public-private partnership, Biotechnology Industry Research Assistance Council (BIRAC).

Dr. N.K. Ganguly

Jawaharlal Institute of Postgraduate Medical Education & Research and National Institute of Immunology

“Neighbouring countries like Bangladesh and Nepal have made major strides in vaccinating children against haemophilus and pneumocci as well the vaccinations against cholera and typhoid are moving ahead. India, being a large complex federal structure is struggling to make these practices a reality. Investing in operational science to determine how to best implement and scale proven interventions will be of the utmost importance in ensuring India’s success in the war on NTDs.”
In order to address the need for greater resources and collaboration to further R&D in India, the Government of India established the Biotechnology Industry Research Assistance Council (BIRAC) to foster innovation and entrepreneurship in the Indian biotechnology sector. Through multiple programmes and grants, such as the Biotechnology Industry Partnership Programme (BIPP), BIRAC supports and facilitates collaboration between academic scientists and industry to promote translational science around the major agricultural and healthcare needs of the Indian people. Currently, BIPP’s projects are mostly focused on healthcare, although only a limited amount of these are related to NTDs. A challenge for BIRAC, and the biotech field, will be to act on the growing need for NTD technologies to support the challenge and needs in the field.

**Dr. Renu Swarup**
BIRAC

“The most important factor for success is strong leadership. An effective leadership team would be able to mobilise more resources and promote the field by transforming the policies that currently undermine R&D for the neglected tropical diseases.”
New Partnerships to Improve R&D

Public private partnerships are critically important to accelerating R&D for NTDs. One such partnership between AstraZeneca and the Drugs for Neglected Diseases initiative (DNDi) began in 2012 to collaborate on drug-compound screening for leishmaniasis, Chagas disease, and sleeping sickness, which together affect nearly 10 million people worldwide.

Novel drug candidates to emerge from this collaboration will bolster the drug development pipeline for new medicines urgently needed by millions of patients. In the new partnership, AstraZeneca will share 15,000 compounds with DNDi, which have the potential for activity against the three diseases. While DNDi will screen the compounds, if successful, the two groups will work together to develop new medicines for NTDs.

Dr. Sunita M. de Sousa
AstraZeneca

“There is an urgent need to deliver new medicines for people who suffer from NTDs. Sharing compounds and working in strong partnership is an effective way of tackling these neglected and complex diseases.”
Integrating Approaches, Applying Evidence and Best Practices

Overview
Ongoing efforts to bolster existing NTD control programmes and build new initiatives can be strengthened by learning from and applying a variety of proven approaches and interventions. It is essential to increase and strengthen the integration of disease specific programmes under a common health care system approach. Underlying this approach is the need to build new collaborations and increase the number and variety of partners and sectors engaged in the field. In addition, lessons learned and best practices from other fields and countries provide different models that could be adapted to the Indian context.

Integrated Programme Approach
Historically, India has taken a vertical programme approach to addressing tropical diseases, with significant successes in areas such as leprosy, lymphatic filariasis and Japanese encephalitis. Within these vertical approaches, different preventive strategies including mass drug administration and vaccination campaigns have been highly effective at reducing the number of cases. These disease specific initiatives and intervention points also strengthen the overall public health infrastructure.

Over the past decade there has been a shift toward an integrated approach that can prevent or control multiple diseases with common pathways of transmission, such as vector-borne or water-borne diseases. The recent WHA Resolution urged countries to “integrate [NTD] control programmes into primary health-care services and existing programmes.” Within India, the National Rural Health Mission (NRHM) is already serving as a critical platform for the integration of various programmes including those whose mandates include many of the

6http://www.who.int/neglected_diseases/WHA_66_seventh_day_resolution_adopted/en/index.html
NTDs, namely the National Disease Control Programme and the Integrated Disease Surveillance Project. Given the reach of the NRHM into endemic areas, many of those most at risk for suffering from NTDs rely upon NRHM services. The National Vector Borne Disease Control Programme (NVBDCP) addresses major NTDs in the country, including kala-azar, lymphatic filariasis and chikungunya; other major tropical diseases covered by the NVBDCP include malaria, dengue and Japanese encephalitis. Zoonotic diseases, however, remain largely in vertical programmes and integrated approaches are only in the initial stages.

Integration at every step from policy at the national policy to programme implementation at the state and district levels will ensure a comprehensive and cohesive approach giving optimum impact and results. While integration at all levels has been initiated, much more can be done, particularly at the mid-level.

In addition to a national focus on strengthening the public health system, cost-effectiveness and maximising funding is one driver behind the shift toward an integrated approach. Vertical programs often deliver excellent results in the short term, yet they can be costly and ultimately unsustainable in the longer term. Integrating across disease specific programmes can improve the delivery of interventions and resulting outcomes at minimal costs, which could improve the likelihood that an intervention is sustained. It is also less costly to add an additional disease target or intervention within an integrated programme rather than to establish a new vertical intervention.

Dr. Kamini Walia
Indian Council of Medical Research

“What gets measured gets addressed, hence it is very important to have correct estimates of the disease burden of NTDs.”
Japanese Encephalitis

An indigenous vaccine for Japanese encephalitis (JE), JENVAC, was launched in October 2013. Developed through a PPP between the Indian Council of Medical Research (ICMR) and Bharat Biotech International, the vaccine is the first domestic JE vaccine on the market. The inactive vaccine was created using an Indian strain of the virus provided by the ICMR’s National Institute of Virology, Pune and further developed by Bharat Biotech. Domestic production of the vaccine will help ensure right sizing and availability of supply to meet a large cohort in the country’s high risk areas, and allow the government to react more quickly in outbreak situations.

The JE vaccine campaign was launched in 2006 and has since been incorporated into the national immunisation programme for routine immunisation in 60 high-risk districts, reaching millions of children each year. A strong surveillance system is able to identify outbreaks in endemic areas. The integration of the vector-borne disease programme and the national immunisation program to combine scientific and technical knowledge with delivery services also serves as a successful integration model. When the vaccine was first rolled out in 2006, the government and its partners garnered significant media attention during the launch of the programme. Increased awareness of the vaccine and JE has been attributed to the successful rollout and high coverage rates. These lessons learned from JE can serve as a best practice example for introducing new interventions for NTDs.

Collaboration and Partnerships

The effective reduction and control of NTDs and integration of different programmes ultimately requires a multi-partner effort beyond that of collaboration between different disease programmes at the centre. The leadership and support of central and state governments for partnerships is critical for successful collaboration. Successful integration and collaboration requires significant coordination and monitoring and evaluation (M&E) to ensure success. M&E in particular is needed to ensure that each partner’s contribution is maximised; for example, if an industry partner is supplying or donating critical medicines, it is the responsibility of the programme leadership and other players to ensure these medicines are distributed and utilised. Ensuring resources for effective integrated programme implementation is also critical. In vector-borne disease control, for example, the integrated programme platform exists, yet often a lack of quality insecticides or pesticides becomes a barrier to reducing transmission.

Collaboration across partners and sectors can contribute critical know-how and necessary resources to maximise programme effectiveness. PPPs are also increasingly recognised as a necessary means to overcome market failures and programmatic gaps to effectively develop and deliver needed tools and services to those who need them most.
Integration Across Sectors – Collaborating with the WASH Sector

Water, sanitation and hygiene (WASH) are inextricably linked to the prevention and control of NTDs. Importantly, one of the five strategies recommended in the WHO’s 2020 Roadmap for the prevention, control, elimination and eradication of NTDs is the “provision of safe water, sanitation and hygiene,” as a lack of access to clean water, improved sanitation or proper hygiene habits significantly increases the risk of infection with several NTDs.

One common NTD linked to WASH is soil-transmitted helminths (STH), whose transmission largely results from poor sanitation or contaminated water. While the main intervention for STH is mass drug administration for de-worming, improved sanitation and proper hand washing could reduce STH inflections by 29%. Even with increasing access to essential preventive measures and curative medicines, the reduction of NTDs such as STH, trachoma and many vector-borne diseases (linked to stagnant water) cannot be fully accomplished without also employing WASH interventions. Yet efforts and funding for WASH interventions and NTDs largely remain separate. Increasing the linkages and synergies between long-term efforts to improve WASH, promote healthy behaviours and strengthen NTD prevention and control programmes is critical for success.
Applying Best Practices – Learning from India’s Neighbours

Many NTD challenges are shared across borders and lessons learned from neighbouring countries can provide a model of best practice. Kala-azar, for example, is endemic to four Indian states as well as areas of Bangladesh, Nepal and more recently in Bhutan. While the number of cases in India is slowly declining, Nepal has eliminated the disease from endemic areas and Bangladesh has made significant reductions. These endemic areas often share similar social cultural factors and also experience a significant amount of migration between them, and stakeholders noted that strategies that have worked well in Nepal may also work well in India. Strategies used in Nepal include a focus on early diagnosis and treatment, including active case finding and integrated vector control with a focus on having complete surveillance data.

In addition to learning from each other’s experiences, collaboration between neighbouring countries is also crucial for success. In 2005, India, Nepal and Bangladesh signed a memorandum of understanding to eliminate kala-azar by 2015. An estimated 186 million people are at risk of the disease between the three countries; joint efforts and research between the countries has helped keep progress on track to meet the 2015 elimination target.
Building Economic and Political Will for NTDs

Overview
Building political will requires multiple stakeholders to attract the interest and attention of key decision makers. Building on the advocacy and leadership of public health experts and medical professionals, attracting new stakeholders to work on NTDs can help increase political attention and resources allocated to these diseases. The London Declaration demonstrates how a high-level, high-visibility platform for commitment and shared action has mobilised the support of numerous players to provide the necessary resources, tools and delivery mechanisms to support country efforts around the world.

Media Engagement
Raising awareness through the media is critical to ensure NTDs are a priority for policy makers. Decision makers may be unaware of the magnitude or location of a problem and increasing media coverage of an issue can help overcome this challenge. Attracting media attention to an issue, by engaging celebrities and other public figures, has helped mobilise public and economic support for other diseases.

The Power of Partnership
New partnerships that widen the discourse beyond public health circles and attract media attention to the poorest and most marginalised communities, which are unfairly burdened by these diseases, will be critical in the struggle to control and eradicate NTDs in India.

Dr. Virander S. Chauhan
International Centre for Genetic Engineering and Biotechnology, New Delhi

“Finding scientific solutions to the multiple challenges of NTDs is possible but political leadership and economic resources are needed to invest in helping largely invisible populations.”
Mobilising New Partners

Potential donors or partners may have low awareness of NTDs or not know where to start in such a large field; raising awareness and providing a concrete opportunity for engagement can turn unlikely partners into allies. The END Fund, which mobilises resources to tackle the five most prevalent NTDs, has utilised this approach of ‘donor education’ to mobilise private funds; many of their funders have never previously funded NTDs.

The END Fund also aims to fill funding gaps for various existing public and private NTD programmes and initiatives around the world. By taking this approach to help fill gaps, rather than launch, pilot or fund programmes from scratch, they are also able to catalyse engagement of partners who may not have substantial knowledge of the field, and thus may be hesitant to become involved. This approach also allows them to work with private companies who want to engage in corporate social responsibility and are looking for avenues to do so, even if NTDs were not previously on their radar.
For decades, partners including pharmaceutical companies, donors, endemic countries and non-government organisations have contributed technical knowledge, drugs, research, funding and other resources to treat and prevent Neglected Tropical Diseases (NTDs) among the world’s poorest populations. Great progress has been made, and we are committed to build on these efforts.

Inspired by the World Health Organization’s 2020 Roadmap on NTDs, we believe there is a tremendous opportunity to control or eliminate at least 10 of these devastating diseases by the end of the decade. But no one company, organization or government can do it alone. With the right commitment, coordination and collaboration, the public and private sectors will work together to enable the more than a billion people suffering from NTDs to lead healthier and more productive lives – helping the world’s poorest build self-sufficiency. As partners, with our varied skills and contributions, we commit to doing our part to:

- Sustain, expand and extend programmes that ensure the necessary supply of drugs and other interventions to help eradicate Guinea worm disease, and help eliminate by 2020 lymphatic filariasis, leprosy, sleeping sickness (human African trypanosomiasis) and blinding trachoma.
- Sustain, expand and extend drug access programmes to ensure the necessary supply of drugs and other interventions to help control by 2020 schistosomiasis, soil-transmitted helminthes, Chagas disease, visceral leishmaniasis and river blindness (onchocerciasis).
- Advance R&D through partnerships and provision of funding to find next-generation treatments and interventions for neglected diseases.
- Enhance collaboration and coordination on NTDs at national and international levels through public and private multilateral organisations to work more efficiently and effectively together.
- Enable adequate funding with endemic countries to implement NTD programmes necessary to achieve these goals, supported by strong and committed health systems at the national level.
• Provide technical support, tools and resources to support NTD-endemic countries to evaluate and monitor NTD programmes.
• Provide regular updates on the progress in reaching the 2020 goals and identify remaining gaps.

To achieve this ambitious 2020 vision, we call on all endemic countries and the international community to join us in the above commitments to provide the resources necessary across sectors to remove the primary risk factors for NTDs – poverty and exposure – by ensuring access to clean water and basic sanitation, improved living conditions, vector control, health education, and stronger health systems in endemic areas.

We believe that, working together, we can meet our goals by 2020 and chart a new course toward health and sustainability among the world’s poorest communities to a stronger, healthier future.

Original Endorsers of the London Declaration

Abbott  Glaxo Smith Kline
AstraZeneca  Johnson & Johnson
Bayer  Lions Clubs International
Becton Dickinson  Merck KGaA
Bill & Melinda Gates Foundation  MSD
Bristol-Myers Squibb  Mundo Sano
CIFF  Novartis
DFID  Pfizer
DNDi  Sanofi
Eisai  USAID
Gilead  World Bank

To endorse the Declaration, add your organisation at www.UnitingToEndNTDs.org
MEETING AGENDA

09:30 – 10:00  WELCOME REMARKS & KEYNOTE ADDRESS
   • Andrew Jenner, Director, Innovation, IP and Trade, IFPMA
   • Anshu Prakash, Joint Secretary, Ministry of Health and Family Welfare

10:00 – 10:45  PANEL: UNDERSTANDING THE NTD BURDEN
   One of the major barriers to controlling and eliminating NTDs in India and elsewhere is having an accurate understanding of the epidemiological burden of the various NTDs. One way to overcome these barriers is promoting and strengthening the use of existing and novel diagnostics through disease management and surveillance systems. By promoting a better understanding of the exact NTD burden in India, and where there are remaining gaps, stakeholders will be able to better target resources and interventions.
   • Chair: C.P. Thakur, Member of Parliament, Former Union Health Minister, Government of India & Chairman, Balaji Utthan Sansthan, Kala-azar Research Centre
   • L.S. Chauhan, Director, National Centre for Disease Control
   • Vasanthapuram Kumaraswami, Consultant, NTD Control Programs
   • Shyam Sundar, Professor of Medicine, Institute of Medical Sciences Banaras Hindu University

10:45 – 11:15  COFFEE/TEA

11:15 – 12:15  PANEL: REACHING THE POOREST AND MOST MARGINALISED
   India has shown through its successful eradication of polio that it is possible to reach the poorest and most marginalised communities with critical health interventions. Significant gains can be made if programmes for different NTDs, which may be overseen by distinct government organisations, are integrated into existing programmes or efforts. Additional attention will be given to community education programs conducted by partner organisations.
   • Chair: A.C. Dhariwal, Director, National Vector Borne Disease Control Programme, Ministry of Health & Family Welfare
   • Atul Shah, Director, Comprehensive Leprosy Care Project, Novartis
   • Ratna Devi, CEO, DakshamA Health & Education
   • P.C. Bhatnagar, Director, Communicable Diseases, Voluntary Health Association of India
   • Vineet Kumar Srivastava, Project Director, Global Health Strategies

Appendix 2

Partnering for Success-Reducing India’s Burden of Neglected Diseases
9 September 2013, New Delhi
**12:15 – 13:00  PANEL: INCREASING RESEARCH AND DEVELOPMENT CAPACITY**

While critically important, existing drugs and diagnostics as well as drug donation programs are not sufficient to achieve control and eradication goals. Sustainable models for product development and operational research are needed to bolster NTD control and elimination efforts. Attention will be given both to existing partnerships between industry, research institutions and other partners and to models for future collaboration.

- **Chair:** Renu Swarup, Adviser, Department of Biotechnology & Managing Director, BIRAC
- **M.M. Gore,** Deputy Director, National Institute of Virology, Indian Council of Medical Research
- **Shirshendu Mukherjee,** Senior Strategic Advisor, Wellcome Trust India
- **Dipika Sur,** Scientist F, National Institute of Cholera and Enteric Diseases, Indian Council of Medical Research

**13:00 – 14:00  LUNCH**

**14:00 – 14:45  PANEL: RECOMMENDATIONS TO REDUCE NTDS IN INDIA**

Participants will share lessons learned and key challenges in addressing NTDs and identify actions that can be taken by participants themselves or the broader community to bolster NTD control programmes and build new initiatives. Avenues will be identified for collaboration with other relevant sectors, such as water, sanitation and hygiene (WASH), vector control, and the education sector.

- **Chair:** N.K. Ganguly, President & Distinguished Biotechnology Research Professor, Jawaharlal Institute of Postgraduate Medical Education and Research
- **Kamini Walia,** Scientist D, Division of Epidemiology and Communicable Diseases, Indian Council of Medical Research
- **Neeraj Jain,** Chief Executive, Water Aid
- **Suman Rijal,** Department of Internal Medicine, BP Koirala Institute of Health Sciences, Dharan, Nepal

**14:45 – 15:30  PANEL: BUILDING ECONOMIC AND POLITICAL MOMENTUM IN THE FIGHT AGAINST NTDS**

Turning the specific recommendations into action will require buy-in from key decision makers across sectors. Representatives from different sectors along with NTD advocates can discuss ways to sustainably increase resources devoted to NTD control and elimination in India.

- **Chair:** Virander S. Chauhan, Director, International Centre for Genetic Engineering and Biotechnology, New Delhi
- **Raj Shankar Ghosh,** Interim Deputy Director, Vaccines Delivery, Bill & Melinda Gates Foundation India Office
- **Ellen Agler,** CEO, END Fund
- **Zakir Thomas,** Project Director, Open Source Drug Discovery Council of Scientific & Industrial Research, Council for Scientific and Industrial Research

**15:30 – 16:00  CLOSING REMARKS**

- **Ranjana Smetacek,** Director General, OPPI

**16:00 – 17:00  TEA BREAK / RECEPTION**