A new short film explains DNDi in a nutshell: our mission, how we partner to deliver new treatments, and what we have achieved in the past 10 years.
‘Connect to Fight Neglect’ is an interactive multimedia portal intended to connect neglected-disease actors worldwide, from patients to policy makers, by offering a forum to voice opinions and perspectives via short videos, photo essays, or opinion pieces.

‘Connect to Fight Neglect’ is a call to everyone involved, directly or indirectly, in neglected-disease R&D to step up and speak out about the successes, failures, needs, and solutions for innovation and access to much-needed health tools for neglected patients.

Objectives

- Highlight the diseases and issues DNDi and partners are working on
- Give a voice to patients, healthcare workers, researchers, partners, policy makers, donors, activists, etc.
- Allow for critical reflection
- Highlight the many partnerships in which DNDi is engaged
- Engage new stakeholders
To develop new drugs or new formulations of existing drugs for patients suffering from the most neglected communicable diseases. Acting in the public interest, DNDi will bridge existing R&D gaps in essential drugs for these diseases by initiating and coordinating drug R&D projects in collaboration with the international research community, the public sector, the pharmaceutical industry, and other relevant partners.

DNDi’s primary focus will be the development of drugs for the most neglected diseases, such as sleeping sickness, leishmaniasis, and Chagas disease; and it will also consider engaging R&D projects on other neglected diseases. DNDi will address unmet needs by taking on projects that others are unable or unwilling to pursue and, as means permit, will consider development of diagnostics and/or vaccines.

In pursuing these goals, DNDi will manage R&D networks built on South-South and North-South collaborations. While using the existing support capacities in countries where the diseases are endemic, DNDi will help to build additional capacity in a sustainable manner through technology transfer in the field of drug research and development for neglected diseases.

VISION
To improve the quality of life and the health of people suffering from neglected diseases by using an alternative model to develop drugs for these diseases and by ensuring equitable access to new and field-relevant health tools. In this not-for-profit model, driven by the public sector, a variety of players collaborate to raise awareness of the need to research and develop drugs for those neglected diseases that fall outside the scope of market-driven R&D. They also build public responsibility and leadership in addressing the needs of these patients.

MISSION
To develop new drugs or new formulations of existing drugs for patients suffering from the most neglected communicable diseases. Acting in the public interest, DNDi will bridge existing R&D gaps in essential drugs for these diseases by initiating and coordinating drug R&D projects in collaboration with the international research community, the public sector, the pharmaceutical industry, and other relevant partners.

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DNDi
Drugs for Neglected Diseases initiative
The Drugs for Neglected Diseases initiative (DNDi) is a patient-needs driven, not-for-profit research and development (R&D) organization that develops safe, effective, and affordable medicines for neglected diseases that afflict millions of the world’s poorest people.

DNDi focuses on developing new treatments for the most neglected patients suffering from diseases such as sleeping sickness (or human African trypanosomiasis), leishmaniasis, Chagas disease, malaria, specific filarial diseases, and paediatric HIV.

The initiative’s primary objective is to deliver 11 to 13 new treatments by 2018 and to establish a strong R&D portfolio for these diseases.
... there was a dearth of research and development (R&D) for neglected diseases. Treatments either did not exist, or did but were toxic, expensive, hard to come by, or difficult to administer: in short, ill-adapted to patients’ needs. Pharmaceutical companies did not invest due to the lack of a lucrative market to recoup investments in R&D and scarce attention was paid to these patients. For HIV, R&D may have been active, but patient access to treatments was in a poor state, and little to nothing was being done for tuberculosis, malaria, and neglected tropical diseases (NTDs).

A decade later, despite the progress that we read about almost every day, still only 3.8% of newly approved drugs target the neglected diseases that account for 10.5% of the global disease burden. Much of the progress in drug R&D over the past decade came about through drug reformulations and repurposing of existing drugs against these illnesses. As recently documented, only 1% of all health R&D investments in 2010 was for neglected diseases. The neglect is still there, despite a decade of efforts and initial successes. To respond to a systemic crisis, we need more!

To help address the neglected disease gaps, new initiatives, including product development partnerships, have flourished and offer innovative ways to develop safe, effective, adapted, and affordable drugs, vaccines, and diagnostics for neglected patients. DNDi was part of this movement, providing an alternative option in order to boost innovation and deliver effective treatments as quickly as possible to those in urgent need. Despite their relative ‘youth’, these initiatives have delivered new health tools and have begun to explore new thinking and practices such as open innovation models, echoed by several international initiatives including drug discovery consortia and intellectual property and patent-sharing mechanisms. Indeed, most major pharmaceutical companies are now committed to neglected diseases R&D. Many provide access to compound libraries, data, and knowledge, whilst others limit their efforts to drug donations. Furthermore, emerging economies, and notably neglected disease-endemic countries, have begun to engage. These are all encouraging developments.

‘Elimination’ has become a real goal for some neglected diseases

Today we hear more and more about ‘elimination’, which was inconceivable a decade ago, and is illustrative of the progress made since. The WHO NTD Roadmap, for example, which defined very specific, time-bound targets for the prevention, control, elimination, or eradication of the 17 WHO-defined NTDs by 2020, is a clear sign that an end could be in sight for certain neglected diseases. However, to ensure that the term ‘elimination’ is not just rhetoric, ongoing commitments will have to be sustained in order to radically change the course of these diseases. The WHO NTD Resolution, adopted at the 2013 World Health Assembly, is a major step forward by the international community, and emphasizes the paramount importance of strong leadership at country level, particularly in disease-endemic countries, for sustainability and success.
Even if today the major actors in neglected disease R&D are still based in high-income countries, numerous innovative initiatives over the past decade have proven the importance and efficiency of building, in endemic countries, the research capacities, manufacturing capabilities, and implementation systems required to sustain a long-term response to the problems inherent in neglected disease R&D.

In addition, the commitment of the private sector, as illustrated by the January 2012 ‘London Declaration on Neglected Tropical Diseases’, emphasized the private-sector support of the WHO NTD Roadmap and its objectives. The neglected disease landscape has benefited from the massive commitment of the Bill & Melinda Gates Foundation, having contributed over a billion dollars to global health, including R&D. Some governments, like those of the UK, The Netherlands, Spain, Germany, France, and Switzerland, also took important steps to increase their efforts, despite the financial crises that have hampered their economies. However, the financial stability of many high-income countries continues to deteriorate and the threat of funding cuts continues to loom.

A need for additional funding mechanisms

Moving into the next decade, additional resources are needed, particularly with a growing R&D drug pipeline with new chemical entities entering the more expensive phase of clinical development. There are very encouraging commitments from emerging economies, for example with Brazil’s recent announcement to support neglected disease R&D. Additional funding has also come from new funding mechanisms such as UNITAID. The challenge today and for the coming years, however, will be to ensure that new funding sources are sustainable and include R&D, such as the Financial Transaction Taxes (FTTs).

For DNDi, even though the six treatments we have delivered are substantial improvements for treatment of patients in the field, they are mainly incremental improvements of existing drugs, and have shortcomings, especially as ‘tools for elimination’ in the long term. As such, DNDi will not have done its job until drugs that are oral rather than infusions or injections, are safe, efficacious, and cheap, and which will likely be used in drug combinations, are developed and delivered to neglected patients.

If we look at what the past decade has to tell us, as DNDi we clearly need to further assess and learn lessons from the challenges we have faced and extract the best practices from our successes. The role of DNDi’s regional offices in endemic regions, along with our founding partners, will certainly need to be strengthened to seize new scientific opportunities as well as to better respond to unmet medical needs. We also need stronger and more synergistic partnerships, and greater agility of the organization to explore innovative pathways to deliver adapted and cost-effective health tools.

The past decade has brought a lot of hope, but there is still a long road ahead in the fight against neglected diseases and the current momentum cannot stop after a few achievements. One thing we have definitely learned is that we need to revisit how we collaborate in order to progress from individual, one-shot, isolated, or fragmented achievements, and genuinely think out of the box about sustainable collaboration.

Connect to fight neglect

‘Connect to Fight Neglect’ is the motto for our 10-year anniversary website, and it is our hope that all of the actors now engaged in neglected disease R&D will reflect with us on what form of engagement that motto implies.

After a decade of innovation for neglected patients, we have learned that if we are to truly ‘bring these diseases to their knees’, we have to ‘keep prodding, keep pushing, and keep searching’ as Dr Margaret Chan recently put it. Indeed, we have to dare to take risks and invest, break down barriers, and move bravely towards our goals for the future.

Dr Bernard Pécoul
Prof. Marcel Tanner

“**We need to progress from isolated and fragmented success to sustainable change.**”
DNDi is an alternative model to develop treatments for neglected diseases and ensure equitable access for all patients.
This WHO report laid out the aims, objectives, and means by which 11 neglected tropical diseases are to be regionally or globally eliminated or eradicated by 2020, with targets for control for the remaining six diseases. This ambitious plan was followed and supported by a new NTD resolution,(2) adopted by all WHO member states during the 66th World Health Assembly (WHA) in May 2013.

The NTD Resolution is a comprehensive call on member states to ensure ownership of NTD programmes and strategies by expanding and implementing integrated interventions, strengthening capacities, and achieving universal coverage.

**Endemic country engagement and the role of emerging economies**

It calls on all WHO partners to support member states in these endeavours, and specifically calls for encouragement of discovery and development of new health tools and for collaboration with WHO to measure progress.

This unprecedented push for and by WHO member states to engage in the fight against neglected diseases comes at a time when positive signs from emerging economies, and particularly those of neglected disease-endemic countries, show that these countries are concretely placing resources in the field of R&D for these diseases.

In June 2011, UNAIDS set out a global plan to eliminate new cases of paediatric HIV infection in the *Global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive.*(3) While one may argue that the dates set forth are overly ambitious, the mere fact that elimination has become a genuine target is important and has implications for how we prioritize projects and determine the profile of the ‘tools for elimination’ that are needed.

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(2) www.who.int/neglected_diseases/EB132_R7_en.pdf  
(3) *Global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive,* UNAIDS, June 2011.
In early 2013, the WHO published the primary reference document for the current state of each of the NTDs, Sustaining the drive to overcome the global impact of neglected tropical diseases, including the strategies for the NTD Roadmap targets and milestones.\(^1\)

DNDi’s project portfolio of treatments to address kinetoplastid diseases, filarial diseases, and paediatric HIV has matured to the extent that it can now support global strategies for sustainable control of neglected diseases, and therefore the elimination of targeted diseases, in addition to providing the tools necessary to support national programmes in the implementation of new, adapted, and affordable treatments.

**Global elimination of sleeping sickness by 2020**

The situation of Human African Trypanosomiasis (sleeping sickness) is significantly different than a decade ago. The number of cases is decreasing, and disease distribution and populations at risk are better understood. NECT has drastically changed the management of the late stage of the disease, and the tools necessary for disease elimination are working their way through the R&D pipeline, notably with two potential oral drug candidates in clinical trials. While this may seem to be reason to rejoice, the real challenge lies in going to the end of the road, getting a rapid diagnostic and a safe oral pill to treat both stages of the disease at the village level, to accompany sustained control and surveillance activities, and doing it in time. Specific and well-defined tools are needed to contribute to sustainable elimination. The WHO states: \(\textit{Reaching the roadmap’s targets for eliminating human African trypanosomiasis depends on increasing access to early, accurate diagnosis, delivering safer and effective treatment; and continuing surveillance.}\(^2\)

**Unprecedented access to compounds and knowledge**

In support of this hitherto unseen momentum for NTDs and of the WHO NTD Roadmap, DNDi and many key NTD actors, both public and private, took part in a landmark event held in London, ’Uniting to Combat NTDs’. The ‘London Declaration on Neglected Tropical Diseases’, emanating from the event, has now garnered support from some 70 organizations worldwide.

DNDi welcomed this mobilization, in particular to address the major gaps in R&D to develop new treatment and diagnostic tools to effectively support the elimination or control of targeted NTDs. Following the London Declaration, 11 pharmaceutical companies committed to negotiating licensing or collaboration agreements to share compounds and knowledge with DNDi. The majority of the commitments have been honoured or are currently under negotiation.

Many of the agreements resulting from the London Declaration are material transfer agreements or licensing agreements. These agreements are a positive step, one which hopefully will lead to broader research collaborations such as those which DNDi has negotiated with several partners. They include the

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\(^1\) Sustaining the drive to overcome the global impact of neglected tropical diseases: Second WHO report on neglected tropical diseases. WHO, 2013.  
\(^3\) Ibid., p. 134.  
\(^4\) Ibid., p. 70.  
\(^5\) Global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, UNAIDS, June 2011.
sharing of compounds, knowledge, and expertise, with pro-
access IP management that secures access to treatments
at an affordable price in all endemic countries, and in some
cases includes commitment of research resources, clinical
development resources, and even implementation of the
approved drug product.

In 2012 alone, new agreements for compound sharing were
signed, for example, with AbbVie (formerly Abbott), Astel-
las, AstraZeneca, BMS, Dupont, GSK, Johnson & Johnson,
Pfizer Ltd., and Sanofi. Other similar collaborations contin-
ued, for example, with Anacor, Celgene, Debiopharm, Eisai,
and Merck (MSD), while development and distribution work
with Cipla Ltd. for ASMQ continued and new work began in
the field of HIV. While not an exhaustive list, these examples
offer insight into the partnerships with pharmaceutical and
biotechnology companies managed by DNDi in 2012.

150,000 Compounds Screened

In 2012, DNDi screened approximately
150,000 compounds, leading to 9 hit series
from Pfizer, 7 from TDR, and 5 from Sanofi.

The 21 series were progressed to lead
optimization, and with an expected attrition
rate, or statistical failure rate, of 90%, two or
more of them could enter into the pre-clinical
stage.

This level of output, which may seem trivial in
absolute numbers, is actually the stepwise
process of portfolio building.

Maintaining a robust portfolio this way
directly expedites the R&D process to meet
the 2020 NTD Roadmap goals.

‘UNITING TO COMBAT NEGLECTED TROPICAL DISEASES’ LONDON EVENT, JANUARY 2012

Dr Margaret Chan (WHO), Bill Gates (B&MGF), CEOs of 13 pharmaceutical companies, the U.S., U.K. and U.A.E governments, the World Bank
and other global health organisations, namely DNDi, announced a coordinated push to accelerate progress toward eliminating or controlling
10 neglected tropical diseases (NTDs) by 2020, in support of WHO’s NTD 2020 objectives.
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Chitar Mal Gupta, Central Drug Research Institute, India

Maria das Graças Henriquez, Oswaldo Cruz Foundation (Fiocruz), Brazil (until May 2012)

Paul Harring, Novartis International AG, Switzerland

Dale Kempf, Abbott, USA

Ana Rabelo, Oswaldo Cruz Foundation (Fiocruz), Brazil (as of June 2012)

Murad Shahzad, Institute for Medical Research, Malaysia (as of December 2012)

Nor Shahidah Khairullah, Infectious Diseases Research Center, Malaysia (until October 2012)

Shiv Dayal Seth, Indian Council of Medical Research (ICMR), India

Faustino Torrico, Universidad Mayor de San Simón, Cochabamba, Bolivia

Mervyn Turner, formerly with Merck Research Laboratories, USA

Muriel Vray, Institut Pasteur, France

Krisantha Weerasuriya, World Health Organization (WHO), Geneva

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Graeme Bilbe, Research & Development Director (from June 2012)

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Ralf de Coulon, Finance, Human Resources & Administration Director
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Jean-Pierre Paccaud, Business Development Director
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Erin Conklin; Jennifer Duran; Jennifer Katz; Oliver Yun
Over 130 R&D partners worldwide

**FOUNDING PARTNERS**

In 2003, seven public and private institutions came together to form DNDi:

- Médecins Sans Frontières (MSF) [Doctors Without Borders]
- Oswaldo Cruz Foundation, Brazil
- Indian Council for Medical Research, India
- Kenya Medical Research Institute, Kenya
- Ministry of Health, Malaysia
- Institut Pasteur, France
- The Special Programme for Research and Training in Tropical Diseases (WHO-TDR)

**DNDi WORLDWIDE**

- DNDi Headquarters (Geneva)
- DNDi Latin America (Rio)
- DNDi North America [New York]
- DNDi Africa (Nairobi)
- DNDi India (Delhi)
- DNDi Malaysia [Penang]
- DNDi Japan [Tokyo]
- DNDi in DRC [Kinshasa]

**CLINICAL RESEARCH PLATFORMS**

- LEAP PLATFORM
- HAT PLATFORM
- CHAGAS CLINICAL RESEARCH PLATFORM
Maintaining growth, achieving balance, with a greater network of partners worldwide

107 FTEs working worldwide

DNDi expenditure totals EUR 150 million since its inception in 2003. In 2012, expenditure amounted to EUR 30 million, +15% as compared to 2011. This increase is mainly due to the expansion of clinical activities in Africa and Asia. The operating loss of EUR 0.05 million is compensated by financial income and a positive exchange rate gain.

Progression towards Business Plan objectives

In 2012, DNDi recruited an additional 18 FTEs (+15 FTEs in 2011), mainly in Regional Offices (ROs): +11 FTEs in Nairobi, New Delhi, Kinshasa, New York, and Rio de Janeiro (+25%) and +7 FTEs in Headquarters in Geneva (+15%). End 2012, DNDi staff reached a first-ever balance between the ROs and the Headquarters, fully in line with the Business Plan 2011-2018.

Steady increase in service provision partnerships in neglected disease-endemic regions to support clinical activities

In 2012, the number of partners and service providers with which DNDi had business relations valuing over EUR 5,000 remained stable (99 in 2012 as compared to 100 in 2011). The increase in Africa is mainly linked to setting up clinical trials, namely fexinidazole for HAT, several studies for VL and HIV/VL co-infection, and paediatric HIV. In Asia in 2012, DNDi ran clinical trials mainly with international organizations based in Asia (but not listed as Asian partners), such as WHO-TDR, OWH/PATH, and MSF, which partly explains the decrease. In addition, some projects in Asia were completed.