Increasing awareness and mobilising resources for neglected diseases

People are denied access to drugs by a variety of factors, including a lack of tools, a lack of funding, and a lack of healthcare infrastructure.
Product Development Partnerships (PDPs) are proving to be an effective means of delivering innovation to the most neglected.

Of the five new treatments delivered for neglected diseases in the past five years, DNDi has delivered three. However, governments and global actors need to scale up efforts to foster innovation on a broader scale. A range of alternative market, policy and financing mechanisms must be developed and implemented to stop the suffering of millions of patients. Sustainable funding and strong public sector support for research and development (R&D) are urgently needed to develop new health tools, including diagnostics and treatments. Recognising the importance of fostering a supportive environment for neglected tropical disease (NTD) research, DNDi works to raise awareness of critical NTD issues and to mobilise public and private resources to meet the needs of the most neglected patients. For example, in June 2008, before the G8 Summit in Japan, DNDi released a statement endorsed by the World Health Organization (WHO) urging the G8 government to support both control programmes and R&D initiatives for NTDs. The Summit Leaders Declaration issued at the close of the conference asserts that the G8 will ramp up commitments to neglected diseases, and includes a specific reference to neglected disease research.

In February 2009, in conjunction with the UN Special Event on Philanthropy and the Global Public Health Agenda [see box], DNDi and Médecins Sans Frontières called for a scale-up of R&D in the form of increased governmental and private-sector commitments to combat deadly neglected diseases that afflict millions of the world’s poorest.

In July 2009, on the occasion of the centenary of the discovery of Chagas disease, DNDi and its partners will launch a campaign to draw attention to the huge gaps in treatments for Chagas patients. The Chagas Advocacy Campaign, with the theme ‘Wake Up. Chagas kills – Time to Treat!’ will bring to light the stark realities surrounding the disease. The burden of Chagas disease is significantly underestimated in official statistics, and few infected patients receive any treatment at all. The only available treatments today are two medicines developed more than 30 years ago with limited efficacy in the chronic phase, toxic side effects, and which are not readily accessible to patients due to complicated supply, procurement and drug registration limitations. New, improved diagnostics and treatments are urgently needed. These initiatives represent some of DNDi’s continuous worldwide activities aimed at increasing awareness about most neglected diseases in various forums.

**MORE SUSTAINABLE RESOURCES NEEDED**

Despite the establishment of PDPs like DNDi and new commitments from public and private donors, funding for scientific and medical innovation for diseases that disproportionately affect the developing world remains inadequate. The R&D funding gap is particularly severe for the most neglected tropical diseases, which offer virtually no commercial market to product developers. Greater investment, complemented with innovative funding mechanisms and incentives, are needed from both governments and the private sector to ensure that these efforts are sustained and strengthened.

Global neglected disease R&D funding in 2007 totalled US$ 2.5 billion, (including malaria, tuberculosis and HIV/AIDS). Of this amount, only US$ 125 million – less than 5% – was spent on the kinetoplastid diseases (sleeping sickness, leishmaniasis, and Chagas disease), which are the focus of DNDi’s efforts. DNDi requires a total of EUR 274 million to achieve its objectives of building a robust pipeline and delivering 6-8 new treatments by 2014. As of April 2009, EUR 110 million

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**UN SPECIAL EVENT ON PHILANTHROPY AND GLOBAL PUBLIC HEALTH AGENDA**

In February 2009, Dr Bernard Pécoul spoke at the UN Special Event on Philanthropy and Global Public Health Agenda, which was attended by more than 400 executives, philanthropy leaders, global health experts, and representatives of UN member states. The main topic was how to strengthen partnerships towards achieving the Millennium Development Goals (MDGs), especially in the areas of neglected tropical diseases and maternal and child health, where progress has been slow.

Secretary-General Ban Ki-moon made the opening speech, and former U.S. President, Bill Clinton offered closing remarks. Both highlighted the heavy burden of neglected tropical diseases on developing nations, and the need for increased commitments from governments, the private sector, academia, and civil society to scale up action against them. Bill Clinton mentioned DNDi as a contributor to the “staggering amount of progress made in this decade” towards reaching the MDGs, even though he acknowledged that much more work must be done to solve global health problems.

Dr Pécoul also participated in the UN press conference preceding the event, where DNDi and Médecins Sans Frontières called for a scale-up of R&D in the form of increased governmental and private-sector commitments to combat deadly neglected diseases that afflict millions of the world’s poorest.
DNDi seeks to ensure balanced financial support from public and private sectors, allowing the organisation more flexibility and sustainability, while also preserving its independence. Accordingly, to promote responsible management, DNDi ensures transparency regarding its decision making and use of donors’ funds.

Up to April 2009, a total of EUR 110 million had been committed to DNDi (see Financial Report), which enabled all of its activities to be funded since 2003. However, DNDi still needs a total of EUR 164 million by 2014 to achieve its business plan objectives.

**NEW GRANTS RECEIVED IN 2008/2009**

- **GBP 18 Million from the UK Department for International Development (DFID)**
  - The UK Department for International Development granted DNDi GBP 18 million over five years in unrestricted initiative funding. This grant builds on the 2005 grant from DFID, which provided the first major government funding to DNDi over the three-year period 2005 – 2008. The grant covers a broad spectrum of drug research, development, and access activities undertaken by DNDi and its partners.

- **EUR 18 Million from Médecins Sans Frontières (MSF)**
  - MSF has committed EUR 18 million over the next six years to DNDi and continues to provide support through its field programmes to the operational and clinical research needed to advance DNDi’s drug-development portfolio. As a founding partner, MSF committed EUR 25 million in start-up funding to DNDi in 2004.

- **EUR 1 Million from the German Agency for Technical Cooperation (GTZ)**
  - The GTZ, on behalf of the Government of the Federal Republic of Germany, granted DNDi EUR 1 million to support discovery, lead optimisation and preclinical projects for Chagas disease and HAT.

- **US$ 200,000 from the Starr International Foundation, Switzerland**
  - The Starr International Foundation granted DNDi US$ 200,000 of unrestricted initiative funding to be used in 2009. The Foundation supports DNDi’s mission to develop new drugs for patients suffering from HAT, VL and Chagas disease.

**ENABLING R&D ENVIRONMENT**

Public leadership is needed to implement policy changes that will support development of new, essential health tools, to ensure equitable access for affected populations; and to contribute to the development of innovative, needs-based measures such as intellectual property management policies to encourage needs-driven R&D, technology transfer, an enabling regulatory environment and strengthening of research capacities in developing countries.

**VARIOUS ADAPTED “PUSH” AND “PULL” MECHANISMS**

Although a comprehensive, sustainable solution to the problem of neglected disease R&D has not yet emerged, governments, experts, and industry have proposed a number of new ideas, including both “push” mechanisms to finance R&D, and “pull” incentives to spur private sector investment.

Some new mechanisms specifically focused on neglected diseases have been launched by donor governments, such as the U.S. FDA’s Tropical Disease Priority Review Voucher, and a number of other public and private initiatives have been proposed or initiated, such as prize funds, UNITAID, the Fund for R&D in Neglected Diseases (FRIND), and the Advance Market Commitment for Pneumococcal Vaccines, or patent pools.

**PATENT POOLS**

In July 2008, UNITAID approved a proposal to establish a patent pool for medicines. The initiative aims to provide patients in low- and middle-income countries with increased access to more appropriate and affordable medicines. Through a collective management structure for medicine patents, UNITAID seeks to improve access to patents and foster the development and production of more affordable and more suitable medicines. The initial focus will be in the area of paediatric antiretroviral medicines (ARVs) and...
new combinations. The principle is to facilitate the availability of new technologies by making patents and other forms of intellectual property (IP) more readily available to entities other than the patent holder.

In February 2009, GlaxoSmithKline (GSK) announced that it is making its IP available to help bridge the gap in research, development, and access to medicines for treatment of 16 NTDs in the least developed countries. GSK offered to put its patents and processes relevant to NTDs into a pool to allow third party access for the development of new drugs and formulations for NTDs to be used in least developed countries.

DNDi welcomes these initiatives. Obtaining access to proprietary IP is one of DNDi’s primary challenges and can take up to two years of negotiations. Accessing proprietary IP through standardised licensing terms incorporated in patent pools could save precious time in delivering new treatments to patients.

At the same time, the WHO has established an expert working group to examine current financing and coordination of R&D, as well as new proposals to stimulate innovation related to Type II (that occur in both rich and poor countries such as HIV/AIDS and tuberculosis) and Type III diseases (those overwhelmingly or exclusively occurring in the developing countries such as sleeping sickness and African river blindness). This group, which will build on the Global Strategy and Plan of Action on Public Health, Innovation and Intellectual Property adopted by the 2008 World Health Assembly, is accepting and evaluating submissions during 2009 and should deliver a plan to the World Health Assembly (WHA) in 2010. While the potential value of some of the new mechanisms for malaria, HIV/AIDS, and TB has been assessed, there has been little analysis of their potential impact on neglected disease research. To help inform the debate, DNDi has commissioned a research study to analyse the value of different funding mechanisms and incentives for the most neglected diseases.

As it has from its inception, DNDi continues to advocate for increased resources to carry out R&D for neglected diseases, and the need for innovative sustainable mechanisms to finance and stimulate it (see box). Moreover, DNDi is itself an example of a push mechanism that has successfully attracted new public and private funding to this field.

DNDi is encouraged by the breadth of ongoing discussions and proposals aimed at stimulating innovation and creating sustainable funding for NTD research. These discussions are critical to moving forward. However, concrete action must be taken if we are to bring new treatments to patients who desperately need them.

### DNDi Supports Calls for Increased U.S. Global Health R&D Commitment

The U.S. government is one of the largest funders of medical research in the world, yet today a disproportionately small level of funding goes to neglected disease research. Recognising this imbalance, DNDi has actively supported calls by the Institute of Medicine, Families USA and the Global Health Technologies Coalition (GHTC) for the U.S. government to increase its commitment to R&D for neglected diseases.

The Institute of Medicine, in a report entitled ‘The U.S. Commitment to Global Health: Recommendations for Public and Private Sectors’, calls for the U.S. to make global health a key component of foreign policy, to double global health spending by 2015, and to support neglected disease research and PDPs like DNDi. Dr Bennett Shapiro, Board member of DNDi, serves on the Committee on the U.S. Commitment to Global Health, which prepared the report.

Families USA’s report, ‘The World Can’t Wait: More Funding Needed for Research on Neglected Infectious Diseases’, found that U.S. government spending on neglected infectious disease research totalled only US$ 366 million in 2007, an “inadequate” sum for diseases that affect 1 billion people. Of that, just US$ 8 million was dedicated to drug development for three of the most neglected diseases – Chagas, HAT and VL.

The Global Health Technologies Coalition, a coalition of over two dozen nonprofit organizations, including DNDi, works to accelerate the development and delivery of new health products to prevent HIV/AIDS, tuberculosis, malaria, and neglected tropical diseases. GHTC educates U.S. policymakers about the benefits of new vaccines, microbicides, drugs, and diagnostics to improve health in developing countries, and has made specific funding and policy recommendations to both the Administration and Congress.

#### Kinetoplastids R&D funding by funder type in 2007

Funding for kinetoplastids R&D was predominantly from philanthropic organisations ($679 million or 54.3%) and public funders in the West and IDCs (40.6% of funding or $50.9 million), making up 94.9% of total global funding.
FRIENDS OF DNDi

In 2007, DNDi inaugurated “Friends of DNDi”, a group established to recognise select individuals who support DNDi’s mission and vision by engaging global influencers, policymakers, and donors to help DNDi succeed in reaching its objectives.


Yves Champey: Former Chair of Genethon Laboratory (France); former Chair of DNDi’s Board of Directors (2003-2007); former Senior Vice President, International Drug Development, at Rhone Poulenc (1995-1997).

Nirmal K. Ganguly: Former Director General of the Indian Council of Medical Research (ICMR). Founding Partner of DNDi.

Stephen Lewis: Chair of the Board of the Stephen Lewis Foundation (Canada); former Minister of Foreign Affairs in Canada; former member of the United Nations Special Envoy for HIV/AIDS in Africa.

Morten Rostrup: Physician in the Department of Acute Medicine at Ullevaal University Hospital in Oslo, Norway; former International President of Médecins Sans Frontières (2001-2004); former DNDi Board member (2003-2005).

Dyann Wirth: Chair of the Department of Immunology and Infectious Diseases, Harvard School of Public Health; former Chair of DNDi’s Scientific Advisory Committee (2003-2007).

Yongyuth Yuthavong: Former Minister of Science and Technology of Thailand; former member of DNDi’s Scientific Advisory Committee (2003-2006).


‘New lycorine-type alkaloid from Lycoris trau- bii and evaluation of antityrpanosomal and antimalarial activities of lycorine derivatives’. Torizuka Y, Kinoshita E, Kogure N, Kitajima M.
VARIous TOOLS, EVENTS AND PUBLICATIONS HAVE BEEN DEVELOPED TO RAISE AWARENESS ABOUT KINEtOPLASTid DISEASES AND DNDI’S ACTIVITIES. SOME EXAMPLES OF WORLDWIDE MEDIA COVERAGE:

- The Lancet Infectious Diseases, ‘Ongoing neglect of leishmaniasis’, May 15, 2009
- Voice of America, In focus, ‘Malaria Day’, April 23, 2009
- Chemical & Engineering News, ‘Paying attention to neglected diseases. The Drugs for Neglected Diseases initiative is mobilizing public/private partnerships’, April 20, 2009
- Europa Press, ‘Una de cada cuatro enfermedades en el mundo tiene como origen el descuido del medio ambiente, según la OMS’, March 27, 2009
- Global Post, ‘When two drugs are less deadly than one’, February 24, 2009
- PharmaTimes, ‘R&D for neglected diseases needs political leadership’, March 4, 2009
- Canadian Medical Association Journal, ‘G8 attention to neglected diseases research welcomed’, August 12, 2008
- SCRIP, ‘G8 urged to address neglected diseases’, July 1, 2008


