As DNDi and its partners blaze the trail together, communications and advocacy play a key role in promoting and supporting projects which address the needs of neglected patients in the most timely and cost-effective way.
In the past few years, awareness of the lack of effective treatments for neglected diseases has been growing. With increasing media attention, essential health R&D has also been included in new policy proposals and funding initiatives.

Established to accelerate innovation for neglected diseases, product development partnerships (PDPs), such as DNDi, are increasingly seen as a new model that provides the drive for collaborative R&D efforts, bringing together public and private donors and researchers. PDPs aim to stimulate R&D, produce needs-adapted health tools, build robust portfolios, and attract new sources of funding from public and private donors.

With its 5 years of experience, DNDi contributes to accelerate the above momentum by strengthening its advocacy, communications, and fundraising activities. DNDi has undertaken a series of initiatives to strengthen its role in advocacy for neglected disease patients and to raise awareness over their plight. In tandem, DNDi’s communications activities focus on providing an accurate image of DNDi’s mission and objectives by promoting a more widespread commitment to neglected diseases. Key messages are expanded upon to convey neglected disease concerns to those who can make a difference in this field.

Throughout 2007/2008, DNDi and its scientific experts actively attended numerous scientific congresses and symposia and provided donors, intergovernmental organisations, NGOs, PDPs, UN bodies, scientists, and the media with experience-based analyses on the challenges facing researchers in the field of neglected diseases and an explanation of DNDi’s role within this field.

**POLITICAL LEADERSHIP**

The dynamic process launched by the Organisation for Economic Co-operation and Development (OECD) in June 2007, which resulted in the Noordwijk medicines agenda resolution asking “governments of OECD and developing countries to demonstrate political leadership to improve the availability of and access to medicines, vaccines, and diagnostics for neglected and emerging infectious diseases,” was a great step forward, yet the WHO Inter-governmental Working Group (IGWG) has been perhaps the most significant process set up to design a global framework for accelerating innovation and improving access to medicines in the developing world.

The elements of the strategy adopted by governments during the 61st World Health Assembly (WHA) in May 2008 include: providing an assessment of health needs in developing countries and prioritising R&D; implementing possible incentive schemes for R&D; improving R&D capacity in developing countries; boosting technology transfer; improving delivery and access to all health products; and promoting sustainable R&D financing mechanisms.

**CONCERTED ADVOCACY EFFORTS**

DNDi has positioned itself, along with other PDPs, as a credible advocate of neglected disease patients, by voicing its concerns and calling upon governments to increase their mobilisation for medical R&D in the field.

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**AWARDS**

**DNDi receives Goodwin Award for its social entrepreneurial approach**

In May 2008, the University of Siena honoured DNDi with its Goodwin Award in the presence of Nobel Prize-winning economist Joseph Stiglitz (left in picture). The award was given to DNDi for its innovative needs-driven approach in making 2 new antimalarials available as public goods, and in engaging public and private partners worldwide, especially in neglected disease-endemic countries. The Goodwin Award is given to entities that – through concrete actions and initiatives – promote well-being and demonstrate entrepreneurship.

**DNDi honoured by the Société de Pathologie Exotique (France)**

In June 2008, on the occasion of the centenary celebration of the prestigious Société de Pathologie Exotique, DNDi, represented by Marcel Tanner, Chairman of DNDi’s Board of Directors, received the Society’s Gold Medal Award given by SPE’s President, Pierre Ambroise Thomas.

**Dr. Bernard Pécoul voted “Doctor of the Year 2007”**

Readers of the French magazine “Impact Médecine” nominated Dr. Bernard Pécoul, the Executive Director of DNDi, as the “Doctor of the Year 2007” for his remarkable work, reflected in the activities undertaken by DNDi in the field of neglected diseases.
In April 2008, a joint statement to IGWG, signed by the International AIDS Vaccine Initiative (IAVI), Medicines for Malaria Venture (MMV), the TB Alliance, the Pediatric Dengue Vaccine Initiative (PDVI), Combating Insect Disease Borne (IVCC), AERAS, and DNDi, called for “adequate and secure funding and on well-coordinated national and international policies that encourage innovation, facilitate collaboration and technology transfer, and ensure access to new health technologies.” Furthermore, and in parallel with these efforts, DNDi released in June 2008 a public statement endorsed by World Health Organization (WHO) urging the world’s wealthiest nations, before the G8 summit in Japan, “to commit resources for appropriate and sustainable financial mechanisms to strengthen existing efforts and to support innovation that are required to meet the health needs priorities of developing countries.”

RSTMH 2007: A STEP TOGETHER IN THE RIGHT DIRECTION

At the centenary meeting of the Royal Society of Tropical Medicine and Hygiene (RSTMH) in September 2007, in London, DNDi and the Leishmaniasis East Africa Platform (LEAP) held a symposium on investigating paromomycin to treat visceral leishmaniasis in Africa. More than 120 key scientists from the Tropical Medicine community attended the symposium to discuss this project. Visceral leishmaniasis is particularly difficult to treat in Africa. The few existing drugs have limited use in the region due to concerns about toxicity, emerging resistance, difficulty of administration, cost, and the often low base level of patient health. The most widely used treatment for VL is sodium stibogluconate (SSG).

“The LEAP group, funded and facilitated by DNDi in Geneva, is currently engaged in discovering what might be the cause for this regional difference,” stated current LEAP Chair, Dr. Ahmed Mudawi Musa of the Institute for Endemic Diseases in Sudan. “It appears that Sudanese patients are not only younger than those in India, but also sicker, as they suffer more concomitant infec-

INCREASING AWARENESS

Various tools (newsletters, videos, website, etc.) have been developed to raise awareness about kinetoplastid diseases and DNDi’s activities. Worldwide media coverage included the following:

- Le Monde, “L’ASAQ, la pilule qui bouscule l’industrie pharmaceutique”, February 27, 2007
- New York Times, “Jump-Start on Slow Trek to Treatment for a Disease”, January 8, 2008
tions, including malaria and pneumonia, during treatment. These factors probably contribute to a poorer clinical response.”

Dr. Monique Wasunna, of the DNDi Africa office at the Kenya Medical Research Institute, commented, “More region-specific research is needed to evaluate new potential treatments. LEAP has the expertise and presence on the ground to do it!”

Dr. Ahmed M. El Hassan, from the Department of Epidemiology and Clinical Sciences, at the Institute of Endemic Diseases of the University of Khartoum, Sudan, chaired this symposium, and his concluding remarks were: “A lot of effort and expertise has gone into this project, with meticulous attention to detail and close follow-up. Important is not only the effort to find a new drug or a combination of drugs to treat VL, but other critical issues have been addressed by the project: capacity building with excellent training of African scientists and support staff, and concrete community participation in development and infrastructure strengthening in rural areas.

I must underscore the fact that the project has brought African scientists in the region together to tackle a disease that knows no political boundaries: an example par excellence of South-South collaboration, about which we talk a lot and do very little.”

— SCIENTIFIC PUBLICATIONS IN 2007 BY TEAM AND PARTNERS

DNDi’s first Stakeholders’ meeting took place in New York in June 2008 and brought together 150 scientists, researchers, academics, NGOs, “Friends of DNDi”, and global health leaders from 25 countries to discuss how international research partnerships can best develop and deliver new lifesaving drugs for neglected diseases.

All speakers shared their operational experiences on different aspects of R&D activities, framing a comprehensive, open-minded, and rich discussion with stakeholders on a diverse range of issues, such as: intellectual property rights (IPR); regulatory strategy; development costs; the role and contribution of public and private partners in fostering innovation; the challenges in strengthening research capacities to conduct trials in remote areas; and the respective roles of PDPs and partners in implementing access plan strategies to better deliver tools to the patients.

Marcel Tanner, Chair of DNDi’s Board of Directors, commented, “To strengthen cross-border and public-private collaboration, our scientific partners from around the world shared critical insights on meeting patient needs, conducting clinical trials, and fostering R&D innovation.” Dr. Bennett Shapiro, Chair of DNDi’s North American Board of Directors, and formerly with Merck, also noted: “In its short existence, DNDi has already shown remarkable capabilities in executing drug discovery and development programmes, as demonstrated by its launch of 2 new drugs for malaria, which were registered in record time. The opportunity to relieve the suffering of neglected patient populations is immense. I am personally delighted to be part of this effort.”

Attendees were also reminded of the urgent needs that are driving efforts in the field of neglected diseases by Argentinian doctor Sergio Sosa-Estani, who remarked, “The patients are waiting. They are waiting for the researcher to research, the politician to decide, and the health worker to act.”

During DNDi’s first Stakeholders’ meeting, the needs of patients took centre stage as participants were reminded that patients are waiting for new and improved tools for essential health. Participants agreed that PDPs can, and must, be strong advocates for policy change. “Let’s move forward, let’s maintain and consolidate”, said Marcel Tanner as he concluded the meeting.

In 2007, DNDi inaugurated “Friends of DNDi”, a group established to recognize select individuals who support DNDi’s mission and vision by engaging global influencers, policymakers, and donors to help DNDi succeed in reaching its objectives. The first “Friends of DNDi” are (as of June 2008):

John Bowis: Member of the European Parliament (EP) for London; Spokesman on the Environment, Health and Food Safety; Author of the report on “Major and Neglected Diseases in Developing Countries” adopted by the EP (2005).

Yves Champey: 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).
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.

A total of EUR 74 million has been committed to DNDi as of April 2008 (see Financial Report). However, DNDi still needs a total of EUR 200 million to achieve its business plan objectives by 2014.

**EUR 200 million still needed!**

Throughout the past 5 years, DNDi has moved from an organisation mainly funded by one founding partner to an organisation with a diverse pool of 12 donors. When DNDi was founded, Médecins Sans Frontières (MSF) - as its sole donor - provided EUR 25 million that was disbursed over its first five years. DNDi has since succeeded in diversifying its funding from both public and private sectors, but is still seeking to achieve a balance between the two. To date:

• DNDi has secured funding from national and local governments including France, Switzerland, Italy (Region of Tuscany), the United Kingdom, Spain, the Netherlands, the USA, and the European Union.

• DNDi has secured the other half of its funding from the private sector through donors such as MSF, the Bill & Melinda Gates Foundation, other private foundations, and individual donors.

In its fundraising efforts, DNDi actively pursues donations from its Founding Partners, foundations, and major donors.

New major GRANTS RECEIVED in 2007

US$ 25.7 million from the Bill & Melinda Gates Foundation

DNDi received a 5-year, US$ 25.7 million grant from the Bill & Melinda Gates Foundation to support its HAT and VL lead optimisation programmes as well as the progression of promising drug candidates through preclinical development.

EUR 6 million from the French Ministry of Foreign and European Affairs

The MAEE awarded DNDi a 3-year, EUR 6 million grant to support preclinical and clinical projects for VL and HAT, as well as two clinical trial platforms in Africa.

EUR 5 million from the Spanish Agency for International Cooperation

AECI granted EUR 5 million to DNDi for essential R&D of drugs for neglected diseases. The 2-year grant of the Spanish government will provide core initiative funding for DNDi.

US$ 2.3 million from the US National Institute of Allergy and Infectious Diseases

NIAID, part of the US National Institutes of Health (NIH), awarded DNDi a 3-year, US$ 2.3 million grant for the R&D of a low-cost formulation of amphotericin B to treat VL.
Governance & People

THE BOARD OF DIRECTORS

The Board of Directors [as of June 2008] is composed of thirteen members, including one patient representative. Each of the six funding members nominates one Board member. Board members serve for a term of four years.

DNDi BOARD MEMBERS

01 Marcel Tanner, Chair; Swiss Tropical Institute (STI)
02 Reto Brun, Secretary; Swiss Tropical Institute (STI)
03 Bruce Mahin, Treasurer; Médecins Sans Frontières (MSF)
04 Alice Dautry, Institut Pasteur, France
05 Christophe Fournier, Médecins Sans Frontières (MSF)
06 Lalit Kant, Indian Council of Medical Research (ICMR)
07 Davy Koek, Kenya Medical Research Institute (KEMRI)
08 Datuk Mohd Ismail Merican, Health Ministry of Malaysia
09 Carlos Morel, Oswaldo Cruz Foundation (FIOCRUZ), Brazil
10 Robert G Ridley, TDR (Permanent Observer of Board), Switzerland
11 Gill Samuels, formerly with Pfizer, UK
12 Bennett Shapiro, PureTech Ventures, formerly with Merck & Co., USA
13 Paulina Tindana, Patient representative; Navrongo Health Research Centre, Ghana

THE SCIENTIFIC ADVISORY COMMITTEE (SAC)

The SAC [as of June 2008] is composed of sixteen prominent scientists with expertise in various scientific disciplines relating to drug discovery & development and/or the specific reality of neglected diseases and neglected patients. They operate independently of the Board of Directors and the Executive team. The SAC has the mandate to advise the Board of Directors on matters related to research and development and choice of projects, as well as the quality of the scientific output.

DNDi SCIENTIFIC ADVISORY COMMITTEE MEMBERS

01 Julio Urbina, Chair; Venezuelan Institute for Scientific Research (IVIC), Venezuela
02 Khirana Bhatt, University of Nairobi, Kenya
03 Marleen Boelaert, Institute of Tropical Medicine, Antwerp, Belgium
04 Pierre-Etienne Bost, Institut Pasteur, France
05 J Carl Craft, formerly with Medecines for Malaria Venture, Switzerland
06 Alan Hutchinson Fairlamb, University of Dundee, UK
07 Chitar Mal Gupta, Central Drug Research Institute, India
08 Maria das Graças Henriques, Farmanguinhos/FioCruz, Brazil
09 Paul Herrling, Novartis International AG, Switzerland
10 Marcel Hommel, Institut Pasteur, France
11 Nor Shahidah Khairullah, Infectious Diseases Research Center, Malaysia
12 Shiv Dayal Seth, Indian Council of Medical Research (ICMR)
13 Mervyn Turner, Merck & Co., USA
14 Muriel Yray, Institut Pasteur, France
15 Krisantha Weerasuriya, World Health Organization (WHO), India
16 Haruki Yamada, Kitasato Institute for Life Sciences, Japan
THE EXECUTIVE TEAM (as of June 2008)

DNDi consists of a team of permanent staff based in Geneva, four regional support offices, a North American affiliate, and two project support offices. The Geneva team also coordinates a broad base of consultants and volunteers worldwide.

DNDI HEADQUARTERS, GENEVA
Bernard Pécoul, Executive Director
Shing Chang, Research & Development Director
Jean-François Alesandrini, Fundraising & Advocacy Director
Manica Balasegaram, Clinical Project Manager (from February 2008)
Gwenaelle Carn, Clinical Project Coordinator
Eric Chatelain, Senior Project Manager
Brigitte Crotty, Executive & Board Assistant
Violaine Dällenbach, Communications Officer (from May 2008)
Ralf de Coulon, Finance, Human Resources & Administration Director
Robert Don, Senior Project Manager
Sally Ellis, Clinical Project Coordinator
Karim Génevaux, Fundraising Coordinator
Caroline Gaere, Fundraising Officer for Major Donors (from March 2008)
Jean-Robert Ioset, Screening Coordinator (from January 2008)
Sadia Shafaqoj Kaenzig, Senior Communications & Press Officer
Jennifer Katz, Fundraising Manager
Jean-René Kiechel, Senior Project Manager, FACT Project (based in Paris, France)
Denis Martin, Senior Project Manager
Céline Méot, Site & Travel Secretary
Janine Millier, Accountant
Béatrice Mouton, Human Resources & Legal Affairs Manager
Jean-Pierre Paccaud, Business Development Director
Sylvie Renaudin, Research & Development Assistant (from February 2008)
Isabella Ribeiro, Senior Project Manager (based in Rio de Janeiro, Brazil)
Ivan Scandale, Lead Optimisation Coordinator (from May 2008)
Ann-Marie Sevcsik, Scientific Communications Manager
Els Torreele, Senior Project Manager
Laurence Vielfaure, Financial Controller

AFFILIATE
DNDi North America, Inc.
Jana Armstrong, DNDi North America Director, USA
Sarah de Tourmente, Development & Administration Manager, USA (from April 2008)

PROJECT SUPPORT OFFICES
Democratic Republic of Congo
Augustin Kadima Ebeja, Regional Human African Trypanosomiasis Platform Coordinator, Democratic Republic of Congo (DRC)
Angèle Ngo-On, Logistician, NECT Project, DRC
Japan
Fumiko Hirabayashi, Japan Representative, Japan
Chris Brünger, Drug Development Advisor, Japan

CONSULTANTS AND VOLUNTEERS
DNDi would like to thank all of the consultants and volunteers who have played a significant role in DNDi’s activities around the world:

DNDi would also like to extend a most sincere thanks to all of the experts, such as the FACT Implementation Advisory Group, who provide advice on various activities.

REGIONAL SUPPORT OFFICES
Africa
Monique Wasunna, Head of Regional Support Office, Kenya
Simon Boló, Finance and Administration Officer, Kenya
Joy Malongo, Administrative Assistant, Kenya

Malaysia
Visweswaran Navaratnam, Head of Regional Support Office, Malaysia

India
Bhawna Sharma, Head of Regional Support Office, India
Sharmila Roy, Finance & Administration Officer, India (from April 2008)

South America
Carolina Larriera, Head of Regional Support Office, Brazil
Bethania Blum de Oliveira, Project Support Officer, Brazil