DNDi
Drugs for Neglected Diseases *initiative*

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Public Research Symposium: "Developing New Treatments for the Most Neglected Diseases through Global Research Partnerships"

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Keynote Speaker:
Richard Rockefeller, EdM, MD, Chair, Board of Advisors, Doctors Without Borders / Međecins Sans Frontieѐs; Chair, Rockefeller Brothers Fund, USA
Richard Rockefeller practiced and taught medicine in Portland, Maine, from 1982 until 2000. Since then he has remained involved in a variety of health-related non-profit activities. He founded and served as president of Health Commons Institute, a non-profit organization dedicated to improving American medicine through the use of computer-based information tools, and informed shared decision making between patients and physicians. He has chaired the U.S. Advisory Board of Doctors Without Borders since 1989, and served on the board of Rockefeller University until 2006. Dr. Rockefeller is also founder and president of Maine Time Banks, an association of service credit barter programs designed to rebuild trust, reciprocity and civic engagement (Putnam's core ingredients of Social Capital) throughout the state of Maine. He serves on the board of Time Banks USA as well. He has chaired the board of Maine Coast Heritage trust since 2000 and is past president of Rockefeller Family Fund.

Transcript of Speech:

I've been asked to talk about how to ensure a sustained commitment to addressing neglected diseases in the next generation. That's pretty daunting. And I'm not sure I will get all the way to the next generation, but actually, if any cause could lead me to give such a talk with optimism, I think that this one can do it. I think there is great reason to be as hopeful about the development of **DNDi [Drugs for Neglected Diseases initiative]** around the world, as we've been in MSF [**Médecins Sans Frontières/Doctors Without Borders**] since its inception, and I'll try to tell you why. I come to you wearing a number of hats – my badge says Rockefeller Brothers Fund, that's true, I'm involved with my various philanthropies of my family. I've also chaired the advisory board to MSF USA/Doctors Without Borders since 1989, and I'm a family physician by training and practice. Relevant to this gathering, I also wear another hat, which is that I almost became a victim of what was almost a neglected disease, and I will tell you the story of that.

In 2000, I traveled on behalf of MSF, to Uganda, specifically to see the sleeping sickness treatment program in northern Uganda – while I was there I also saw what Epicentre was doing with malaria in the south of Uganda – but most of the time we spent with the sleeping sickness program. While I was there, I will say that I saw patients treated with melarsoprol… I didn't see any die from it but I saw the kind of pain that they experienced in taking that awful drug. So I was already impressed, and within the same year, MSF was talking about developing the **Access to Essential Medicines Campaign** – in fact, it was already underway and that's part of the reason I went to Uganda: to see what it was we need access to. When I returned from Uganda, I actually noticed a few odd

things: I had swollen feet and I felt tired and, as a typical doctor, I ignored it…and decided it must just be some weird thing I had picked up in Uganda and I'd just wait and see if it went away and then I got busy with my life… I stopped exercising because when I did I got out of breath and again, typical doctor, I figured "just don't exercise and ignore it." But in September, it was no longer something that I could ignore – this was one year, almost precisely, before the attack just out side of this building [7 World Trade Center] and I had my own terror attack when I got blood tests done and found out that I had leukemia. And…the type of leukemia I have, called CML, was actually considered for a while, an orphan disease, in this country, because there were few enough people that [even though] there's great scientific interest in it because of the nature…the type of leukemia, the type of cancer it is, it lent itself to very careful study and, probably it's better understood than any other cancer – but pharmaceutical companies were less interested because there were fewer patients to treat and so there was a question, even as I was being diagnosed with the disease, whether pharmaceuticals would proceed with the development – for the development of a drug that has come to save my life. The drug is called Gleevec, many of you may have heard of it, it's the most successful designer cancer drug, the most successful cancer drug of any kind ever produced. It has become the model for all other cancer research – everybody hopes to have one pill that can treat all cancers in the future, and that is not inconceivable. It's also true that this drug costs about 100 dollars a day, and I will probably have to take it for the rest of my life, so it's about 35,000 dollars a year for Gleevec. And Novartis, who has developed it, has a program by which they supply people in the developing world – to some extent, but there's an awful lot of people who obviously can't afford it, they cannot treat everybody, you know the lifetime incidences 1 in 50,000 so that means there's an awful lot of people around the world who will have this disease and not be treated…Over the next couple of years after I was diagnosed, I went from being a generalist – I am a family doctor – to being a sub-sub-sub-specialist: I learned everything I could, everything, I think, almost everything there is known about CML and an awful lot about other leukemias and other cancers. And I had the opportunity to look at what was being done on behalf of cancer research around the world – an utterly fascinating and marvelous story – it is – because the rate of discovery had increased, probably ten-fold or more since I was in medical school, 20 years before that, and I will say to you that it has probably increased almost ten-fold since I was first diagnosed in 2000. So, I'll come back to this, but one of my reasons for being optimistic is that the science, and the tools for understanding disease and developing treatments has advanced just miraculously fast. I

will also say that the - that my interest in the Access to Essential Medicines Campaign at MSF and then, as DNDi was being conceived, was also very much increased by own condition just on the basis of fairness alone. It is not fair that in the western world we can develop diseases and get to stay alive – by the way the median survival for CML at the time I was diagnosed was 4 years, I've had it for 8 years and I'm perfectly healthy, so I am…it's just a…I am the beneficiary of a miracle, but it ain't fair that people around the world can't get the same kind of benefit. And therefore, it's worth working to change all of that.

I'd like to just spend a few minutes on what I have learned about both drug and diagnostic development and also, what I've learned about DNDi and what I believe about DNDi given my experience with it and with MSF the various factors that lead to me to be extremely optimistic. As I mentioned, the science is moving at an extraordinary rate. When I was first diagnosed there were polymerase chain reaction tests able to detect tiny quantities of the aberrant DNA that is in my system that causes my white cells to become leukemic. And the PCR tests have advanced considerably and become standardized and so forth and they can be used for any number of types of DNA – but there are researchers now who are developing much, much more, much faster, cheaper PCR tests. Researchers in Boston have come up with a PCR on a chip that can simultaneously detect the presence of any of 20,000 different DNA sequences at probably 1/100 of the cost of what PCRs were costing when I was first diagnosed – that's one example only. There are obviously the Genomics, the Proteomics, that we have developed – all of these are going to be able to be brought to bear, and… we used to look upon parasitic diseases, such as those in the four tops among the neglected diseases, as immensely complex. It's my belief, as a sort of scientist, but as a non-researcher, but as somebody who has been spending time in this field, that we are going to be…if we really can take those advances in cancer research and various research of problems in the western world, and apply them to these neglected diseases, we'll see…what Bernard was telling you about is astonishing – the rate of success already of DNDi – we can multiply that by several factors and I believe we will. There are obstacles, obviously - in the course of my looking at how **Gleevec** came to be developed, and in subsequent investigations as to what is in the pipeline for leukemia, I've seen the best and the worst and the worst is actually pretty bad. I hate to say this, and those of you who are representatives of pharmaceutical industries may or may not appreciate it, but there's some very, very bad action in the pharmaceutical industries – not only are pharmaceuticals failing to develop life-saving drugs because they won't be profitable, but there is very clear evidence of blocking the attempts of competitors to develop those drugs,

undermining…there's some bad stuff going on. The good news is that even in the worst of the pharmaceuticals, we really have allies. I would say almost uniformly, probably uniformly, I would say the scientists working in pharma are on the side of really taking care of people. It's the folks running it – it's the management - in the 25 years that I've been involved in pharmaceuticals – top management has gone from kind of a balance of humanitarian scientists management CEOs on the one hand, balanced with the financial folks on the other, the bottom-line profit-maximizers, and at least in the big pharmaceuticals that I've tracked, that balance is almost…it's skewed all together to one side and it's the bottom-line. But as I say, we have allies within the biggest of the pharmaceuticals and then of course this is not a monolithic industry, as…by the people represented here today, not all pharmaceutical companies are the same and there are those who are willing to take great strides on behalf of the most needy people around the world. Other advantages that we have, as Dr. Olobo, mentioned, information technology has advanced extremely rapidly. Quite honestly, I think we've only seen the beginnings of what information technology can do in the developed world, and I think very rapidly also in the developing world in terms of supplying information and diagnostic support so forth. DNDi itself, the very existence of DNDi, is one real cause for optimism on my part. The fact that, as Dr. Shapiro said, it came out of MSF, who's willing to tackle impossible problems and very often succeeds in solving them, gives me a great deal of hope. But I also think – and the way you all are approaching DNDi, as a global consortium, it's being very carefully assembled, it's in everything it has tried, as far as I can see it's been successful so far – that also stands in its favor. I would also say that the willingness of the world, of people around the world who are interested in humanitarian issues, to consider strategic approaches not simply direct, immediate humanitarian assistance, that is… that's growing. We will always need people who will reach out to victims of violence or of earthquakes, or what not, but my experience in fundraising for MSF leads me to believe that people are much more interested than they use to be in strong strategic approaches. My best example is the Plumpy'nut example in treating malnutrition around the world. I give talks and am involved in fundraising events quite often and, quite to my astonishment, the most questions we've gotten over the past couple of years have been about Plumpy'nut and it's potential ability to – as a technology in a sense – to really address and potentially solve the problem of malnutrition in children under the critical ages of 6 months to 3 years. And it's partly how you tell the story, and MSF has done a good job telling a story and it's a great story to tell and many of you probably saw Anderson Cooper present that on **60 Minutes**

and the kinds of things that we're going to need to do with DNDi. Get great stories and great presentations of the story. But it also is a shift in the interest of people who are willing to fund and I think we need to tap that in DNDi and if we do – I mean, yes, whatever it is, 430 million sounds like a lot, maybe if the dollar goes down it will be very easy to raise 430 million dollars around the world 'cause it won't be that much at all – just kidding…but it's actually been – when MSF has been able to show when there is concerted, prolonged, smart attention to these problems that affect people around the world, folks who are able to give, are willing to reach out and do so. And this is a matter of intelligent media attention, intelligent communications – I love the slide that was just up here a minute ago, "our governments have sleeping sickness" – those kinds of graphics and that kind of presentation really are starting to grab people, not just around the starving babies, but around the strategic issues. So I think that we're going to make it in funding. Obviously, those of us around this room that are involved in fundraising and funding, we need – we have some work to do…and one of the things I try to convince my colleagues at MSF is: there shouldn't be a continual split between the folks doing the work on the ground and the folks raising the money. There's a tendency to kind of poo-poo the fundraising side and say "that's a little bit dirty and somebody else should do that – we do the pure stuff in the field". I'll tell you that it works best – first of all: money applied to the right things is a very, very useful thing and it really works best to raise that money if the folks doing the work on the ground are also involved in fundraising so I'd advise all of you who are passionate about this, involved in it, to get involved with that side as well. And if we can do all of those things and if all of the rest of what I've said is true about the forces in our favor, I really think that this is going to accelerate and be a huge successful effort in a very short time...So I congratulate you all and thanks for inviting me here today.