

Treatment for All – Transcript from the President’s Address

George Rivard, Congress President

It is my privilege and honour to welcome the first speaker of this plenary session program, the president of the World Federation of Hemophilia, Mark W. Skinner. Mark Skinner has an extensive and lifelong involvement in the field of bleeding disorders. Since Mark was elected president of the World Federation of Hemophilia in October 2004, he has been a tireless advocate for hemophilia care and for the pursuit of the vision of the World Federation of Hemophilia to achieve treatment for all who have inherited bleeding disorders. Mark is a former president of the board of the U.S. National Hemophilia Foundation (NHF) and he currently sits on the medical and scientific advisory committee of the NHF. He was the inaugural recipient of the National Hemophilia Foundation distinguished leader award, and in 2003 he was named their humanitarian of the year. Mark has served in numerous capacities as an advisor on critical blood safety supply and viability issues, including as a member of the U.S. secretary of health and human services advisory committee on blood safety and availability. It is my privilege to introduce Mark Skinner to deliver his presidential address.

Mark Skinner

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Good morning. Today, it’s my privilege to share with you our vision for improvement for the future of the WFH and for all those with bleeding disorders around the world.

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Over the years, we’ve all come to learn the difficult reality of living with hemophilia. Whether we have it personally, whether it’s in your family, whether you’re a healthcare provider or a government official, we know the difficult challenges of living with hemophilia. Since you last saw this data in Bangkok, though, there has been a significant change.

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There’s been a 14 per cent increase in the number of patients diagnosed with hemophilia and other bleeding disorders around the world. In a short 18 months, this is a truly remarkable achievement.

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Of course the work of the WFH is to change this reality and to continue to improve – to improve treatment where it doesn’t exist and to maintain treatment and care where it already does exist.

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Look at our global family: 109 member nations belong to the WFH and in fact at this Congress, three more are joining us. Japan, Bahrain, and Lesotho will become members of our organization and our global family. We continue to grow and as I said last night, in 43 years it’s been a remarkable change since Frank Schnabel, our founder, sat around his dining room table in Canada with six organizing members to start this organization.

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Of course it takes more than just our national members. It takes a winning coalition of our national members along with healthcare professionals, doctors, dentists, laboratory technicians, physiotherapists, and orthopedic surgeons. It takes our partners in government and health ministries. And of course it takes our corporate donors, and it takes our friends in industry and regulators. Together we make up a winning coalition— we’re a global family that’s making a difference in the lives of so many around the world.

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Over the course of this past year, we've had the opportunity to visit with each of these stakeholder communities to refine our mission, to define our goals, and to unite our community around a singular vision for the future, and that vision is "Treatment for All."

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Today it's my privilege to share with you our strategic plan, our vision for improvement and the work of the World Federation and what it will be in the years ahead.

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When we talk about the words Treatment for All, it really means that treatment will be available for all patients with inherited bleeding disorders regardless of where they live in the world. Treatment for All means that patients will have access to safe and effective treatment products. Treatment for All means that care will be available by a trained team of specialized healthcare professionals. And Treatment for All also means that our global family should and must include all those with bleeding disorders, not just hemophilia, but patients with von Willebrand disease, the rare factor deficiencies, and inherited platelet disorders.

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Our strategic plan is based on seven strategic themes. The first is improving treatment where it doesn't exist; the second is sustaining treatment where it already is well established; the third, as I just said, is making sure that we provide treatment and care for those in our global family, those with von Willebrand disease, inherited platelet disorders, and the rare factor deficiencies.

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The fourth strategic theme is education and training, the core of what we do to reach out to patients and healthcare professionals around the world. The fifth strategic theme is safe and effective treatment products and of course the quest for a cure. Our sixth is diversifying our financial base, and the last, of course, in any strategic plan, you've got to make sure that the organization is positioned and adapted to achieve the goals ahead. Over the next 30 minutes, it's going to be my pleasure to share with you the items that overlie each of these strategic goals and to give you a little bit better understanding of what the work of the World Federation will be in the years ahead.

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So let's look first at our strategic theme of improving treatment in emerging countries.

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The work of the World Federation is a two-track system: we have our general country program activities and we have the work of our multi-year country programs, which include targeted development activities in countries. And we will also be continuing the Global Alliance for Progress. As I said earlier, 70 per cent of the patients in the world still are not diagnosed, so we will place a heavy emphasis on ensuring that we continue to improve diagnosis around the world. And certainly access to treatment and treatment products is one of the core aspects and we will be working there as well.

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Let me just give you a picture of what our program activities look like. When an organization or a country – a National Member Organization – comes to the WFH we go through an exploratory phase where we have an opportunity to learn about the country. And then from there they'll enter into one of two program tracks: they will either enter into our general program activities or we will move into a more intensive program, our multi-year country program.

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Let's talk first about the general program activities.

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The general program activities include many of the things with which you're already familiar, things which many of you are already involved in and have come to know as core parts of the World Federation of Hemophilia: our National Member Organization skills training workshops; the organization and centre twinning programs; our humanitarian aid program; the medical training fellowships, including the IHTC centre fellowship training program; our multidisciplinary workshops for the other healthcare providers; and the laboratory quality assurance scheme. Countries should view these general program activities as a pathway to sustainable care in and of themselves.

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These general program activities also are part of our multi-year country programs.

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The multi-year country programs are two part: first are our targeted, country development activities and the second is the Global Alliance for Progress. The distinction between these two is really one of scope. In the targeted country development activities we will be working on one of five core development areas – possibly two or three – but we will be focusing on just a portion of the overall development program. We'll be working on government support, the healthcare delivery system, the medical expertise and diagnosis, the availability of treatment products, and building the capacity of our National Member Organizations.

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In the GAP program – the Global Alliance for Progress, our most intensive program – we work on all five of these aspects simultaneously. Countries should understand that if they aren't a part of the GAP program, it doesn't mean that they're missing any of the benefits of these programs. In fact, the training manuals, the programs, and the tools that we're developing through the GAP program are being used throughout the work of the WFH, whether it's in the general country activities that I mentioned in Track 1, our country programs, or in the GAP program, these tools are being used and utilized to make a difference in the lives of patients with hemophilia. And since we're talking about the lessons we've learned, let's also talk about some of the achievements of the GAP program in a little bit more detail.

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The GAP program was founded in April of 2003 to close the gap in care between those living without access to treatment and proper care and those that have it. Over the past three years, this program has evolved substantially, both in terms of the number of countries involved as well as in terms of the expertise and the quality of our work. We are grateful to our funding partners who have made this possible and certainly to each one of you on the ground in the countries that are participating in this program. You are making a difference in the lives of people daily. So let me tell you about some of the accomplishments.

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One of the greatest achievements of the Global Alliance for Progress is the fact that we have signed agreements with six countries to establish national hemophilia care programs. And let me tell you what this means: this means that ministries of health have signed an agreement to establish a program and place hemophilia on the national healthcare agenda *and* they have made funding commitments. A truly remarkable achievement, and we expect over the course of this year, one or two more countries will be taking this important step. Of course, there's more.

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During the course of these past three years, over 3,000 healthcare professionals have been trained through the Global Alliance for Progress and over 1,500 patients have received education and training.

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But we also know that it all begins with diagnosis. If we don't know where the patients are, we can't treat them. We can't develop a national program. In three years alone, we have diagnosed and we have supported programs for the diagnosis of over 5,000 new patients and they are now registered and properly documented in these ten countries. And this is a remarkable pace because if you do the arithmetic that means somewhere in the world five new patients in these ten countries are being diagnosed every day. And as I said earlier, this is just in the GAP countries. Globally, we've increased the number of patients diagnosed by 14%.

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Of course the next step after diagnosing patients is bringing them treatment, access to affordable care, and products. And this is one of the essential pieces of treatment. WFH programs are proving to be a catalyst for achieving access to clotting factors concentrates. And let me just brag a little bit more about the work of the World Federation of Hemophilia. And it's not just us: when I say the World Federation, I mean our global family that's assembled here in this room.

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Some of the achievements over the past 18 months since we were together in Bangkok. In China, the Guangzhou Ministry of Health has established a healthcare reimbursement system and insurance mechanism for patients with hemophilia and clotting factor concentrates. In Egypt, there has been a one-year increase of 1 million units in the amount of products being purchased by the government. In Russia, a 250 per cent increase in the amount of products being purchased by the government. And in Thailand, the government has announced this year, the first national budget for clotting factor concentrates, moving the Thai treatment standard from cryoprecipitate to clotting factor concentrates.

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In Georgia, there has been a 50 per cent increase in the IU per capita available to treat patients with hemophilia. In Mexico, the social security insurance system has now reached a level of 0.5 IU per capita for the patients in those programs. And in Saudi Arabia, there has been a 100 per cent increase in the amount of products that is going to be purchased announced by the ministry of health.

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But of course these are gains over the last one or two years. The real key is, are these gains sustainable? So I want to take you back to look at a couple of our early country programs, Chile and Uruguay.

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Both of these programs ended a couple of years ago, and as you see from what's on the slide, the gains that we achieved from the intensive efforts of the WFH are being sustained today. The WFH does make a difference and the numbers show it.

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Of course we also know that every one in the world and every government can't afford clotting factor concentrates, so we have some other initiatives underway as well. We need to find ways to innovate to enhance access to safe and affordable treatment. Certainly one of those is the management of the existing resources that are available in the countries, and this year the World Federation published our first set of treatment guidelines. This publication has proven to be extremely useful around the world for ministries of health and for clinicians. Whether abundant resources are available in a country or whether they're scarce, this treatment guideline allows trainers and clinicians and governments to rationalize and optimize the use of clotting factor concentrates in the treatment for their patients. Of course we're working on humanitarian aid and pricing as well. Let me tell you first about humanitarian aid.

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Last year we received donations that went to over 35 countries, providing treatment and care for 4,200 children and their families around the world. As we sit here at this Congress, we're also marking the tenth anniversary of our humanitarian aid program. And over the past ten years, 125 million units of clotting factor concentrate have been donated, reaching over 30,000 patients around the world. Not only are clotting factor concentrates an important tool for taking care of emergencies and catastrophic diseases, but many of the access achievements and expansion of care available in a country actually began with clotting factor concentrates as the catalyst to achieve the governments purchasing products. These donations are extremely important and vital to what we do.

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We're extremely grateful to the companies that make these humanitarian donations but as you can also see from the data at bottom of the screen, the donations and the products available to the WFH were extremely variable from year to year. We will be working in the years ahead to try to stabilize and to increase the predictability of the humanitarian aid donations. But we're not relying solely on the companies for these donations.

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The WFH has another new initiative underway, one that we call Project Recovery. This is to ensure that no factor VIII and factor IX proteins are wasted. As a number of countries have made the decision to transition or to change to recombinant products as the standard of care, the plasma that they collect in the countries and the proteins for factor VIII and factor IX in the plasma are going to waste. For example in Canada, 150,000 litres of plasma are being collected, which could produce 15 million units of factor VIII or 30 million units of factor IX. We're piloting an innovative collaboration with the Canadian plasma. And as we're here in Vancouver, I want to pay special recognition and thanks to our Canadian partners for helping to make this possible, the Canadian Blood Services and Héma-Québec, who are working with us to donate this unused plasma to the WFH. The plasma will be sent to South Africa, and the National Bioproducts Institute in South Africa is working to fractionate this unused plasma into products that can be used for humanitarian aid in the sub-Saharan African region. And since we've announced this pilot program last year, we've had expressions of interest from a number of other countries around the world wanting to donate plasma for this same project. If this pilot is successful, we see great opportunity to expand this program in the years ahead.

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We've also been talking about pricing. We talk about what we call a twin-track pricing system or a differential pricing scheme for clotting factor concentrates. This would be a program in which there would be a different price for targeted emerging countries to have access to clotting factor concentrates at what would be an affordable level for them. There is a successful precedent for these kinds of scenarios, both in the areas of HIV/AIDS test kits as well as in childhood immunizations. So we've had conversations over the course of this year with the World Health Organization and members of industry to determine their interest in moving forward with such an initiative, and I'm pleased to report that there is interest. While bringing this project to fruition is still many years away, I wanted you to know that we've begun and that we are also working in this arena.

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Let's turn our attention to the second theme: ensuring continued development and care for those that live in countries where health care is already well established.

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While the core focus of the World Federation remains taking care of those and helping those in emerging and developing countries, we recognize that the healthcare environment in established countries is also quite difficult: that there are many pressures on the governments, that healthcare priorities change over time, and as we've achieved great successes for hemophilia, we can't let governments lose the focus. The gains that have been achieved continue to be important.

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Certainly many of the programs we have throughout the World Federation are applicable to countries whether they are emerging or established. Programs such as our global forum on blood safety and our data collection efforts, these cut across all countries of the world. But over the course of this year we're going to be spending more time listening to our member countries that have established healthcare systems to find out what we can do to better serve them to make sure that the health care that they've achieved is sustained. And certainly we are also looking, as the World Federation grows and expands its reach around the world, we're going to be asking those established countries to do more and provide us more volunteers to support the various programs and activities. We certainly can't do it all from Montréal, we need the help of volunteers around the world.

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Let me tell you about just one initiative that we've begun at the World Federation already this year. We call this our European Advocacy Initiative. This is going to be a series of three workshops held in different regions of Europe over the course of the year. I think we all know the changing presence and importance of the European Union, the work that is occurring in Brussels to look at the healthcare systems and regulations across Europe. So we brought together patient groups from different regions of the world to try to help unify them, to try to help develop skills, so we are prepared to meet the challenges ahead of lobbying at the European level. And we are doing this initiative in cooperation with our partners in Europe, the European Haemophilia Consortium. Secondly, we're working on a monograph that actually lays out some of the challenges that will be faced in countries so that again, countries can be prepared and anticipate a monograph that looks at the challenges of sustaining hemophilia treatment centres as the model of care.

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Our third theme is enhancing access to make sure that the World Federation of Hemophilia is truly representative of our entire global family.

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As you can see from this data there is a pressing and compelling need to take care of these patient populations. They are mostly undiagnosed, and often if diagnosed, are misdiagnosed. Potentially 6 million patients with von Willebrand disease show clinical signs and symptoms and require treatment, but according to our survey data, less than 1 per cent of that patient population has actually been diagnosed. By reaching out to these patient populations, we will expand our base, we will expand our base of support, and we will attract new support and interest in these countries.

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The issues facing these patient populations really are not that much different from those that face the hemophilia population: access to safe treatment, improved diagnosis and data collection, and expanding training and educational opportunities for those patient populations and the healthcare providers that take care of them. Later this year we'll be announcing the task force that will be looking at ways to establish pilot programs in a number of countries to begin to address these areas to try to build and define a program for the WFH in this area in the years ahead.

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Our fourth theme – sharing knowledge and building capacity – underlies and supports the previous three that I've talked about.

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Sharing knowledge is one of our core activities and we will continue to develop educational and training tools to meet the needs of our member organizations. And we will continue to do training nationally, regionally, and globally. Through the World Congress and our other meetings, we will work to maintain our leadership position as the meeting place for the global bleeding disorders community.

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Earlier this year we actually redesigned and re-launched the WFH website to complement our new strategic vision. And through our website this year we're actually going to be expanding educational opportunities. For the first time, later this year, we will be launching web-based training programs for healthcare professionals in the various disciplines around the world.

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Here are a few recent examples of some of the WFH publications. We currently have over 80 publications available electronically and in print in our library, and many, if not most, of these are available in multiple languages. *Hemophilia in Pictures*, one of our newest publications, is proving to be the most popular publication of the World Federation of Hemophilia. It is a web-based training program that bridges language barriers and helps educate patients about hemophilia in a very simple, pictorial way. In just a year, over 35,000 copies of this publication have been distributed around the world. And because of its success we're looking at new ways to expand this publication and use it to bridge language barriers and to reach other parts of the world.

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Our World Congress – of course that’s why we’re all gathered here. Over the past decade attendance at this World Congress has more than doubled. And I believe this Congress will set a record. We don’t have the final numbers yet but we’re very close to reaching the 4,000 mark. As I said last night, over 110 countries have already shown up for this meeting. And I’ve already made two trips to Istanbul to get ready and prepare for the 2008 Congress. So our next meeting of this group will be in Istanbul in 2008.

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Our fifth theme is promoting access to safe and improved treatment, and of course, the quest for a cure.

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Treatment for All means that safe and effective clotting factor concentrates will be available to all those with bleeding disorders regardless of where they live in the world. The WFH will continue to work with governments and patients, health ministries and regulators, to address the adverse events associated with treatment and to find ways to innovate and improve treatment.

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Two years ago while we were gathered in Bangkok, we as a global community faced a major challenge: the serious threat that the World Health Organization would remove clotting factor concentrates from the essential medicines list. Together, we faced this challenge, and we won! It is thanks to the people in this room for making that happen. The committee at the World Health Organization recommended that clotting factor concentrates stay on the list and thus having once again established the paramount importance of clotting factor concentrates for the treatment of bleeding disorders, we are faced with a number of choices.

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And when we think about the choice of clotting factor concentrates – there’s both plasma-derived and recombinant products – the World Federation of Hemophilia views both choices as equally important to our community. Both enjoy a robust record of safety and neither one alone would be sufficient in supply to meet our global need. There’s a wide range of products; they differ in cost and the different economic capacities of the countries mean that different purchasing decisions will be available for different countries, and different product selection choices are important for different patients. So we need to maintain this diversity, we need to ensure that we have the flexibility to make sure that we’re prepared for the challenges ahead and any future unforeseen events that could disrupt the supply.

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But this doesn’t mean that there is no risk to the treatment. Historically, as a global organization we focused on pathogen risk such as HIV and hepatitis and more recently, variant CJD. But it’s time that we define risk more broadly.

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The development of inhibitors is the most adverse risk facing our hemophilia population today. Fully 20 to 30 per cent of patients with severe hemophilia are at risk of developing an inhibitor in their lifetime. So we must have global data to better understand and to address this problem. We need to understand the incidence of inhibitor development, the risk factors for developing inhibitors, and the best strategies for the treatment and management of inhibitors. The WFH is ready to be a leader to bring the global community together to address what has to be a global data collection need.

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But of course our wish doesn't end with treatment. There also is the future and we know that treatment is just a therapy. We also look forward to the day when there will be a cure. Advancing a cure for hemophilia is not a challenge that can be met by one country, one organization, one company, or nation. It's going to take a global effort, it's going to take a community effort. We all must be involved. The development of gene therapy has had great potential for many hereditary diseases, including hemophilia. Gene therapy's success in the pre-clinical arena over the past 15 years has been accruing and the World Federation of Hemophilia strongly supports building upon these successes. However, in the near term we also are looking forward to improved and more efficacious products. We've been hearing about research for therapies that could result in a one-weekly dosing and this type of treatment has the opportunity to truly revolutionize care not just in established countries but around the world. And we look forward to the day when these therapies are available as well. Of course to achieve everything I've just talked about takes more than the hard work of the friends and families that are in this room.

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It takes expanding and diversifying our base to make sure that we have the revenues to meet the challenges ahead.

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The demonstrated success of our programs is impressive: we have a compelling case to make to funders and donors and they should want to give to our work because we can prove to them that their dollars do make a difference. But we also need to expand and diversify, we need to do more global fundraising. We need to expand our work with our affiliated organizations, such as an organization we have in the United States called the World Federation of Hemophilia USA that works on our targeted humanitarian aid programs and some other fundraising projects. And we also need to find ways to reach out and identify non-pharmaceutical sponsors. I do believe it's important for you to understand that all of the things that I've talked about today will require financial discipline and a programmed, sustained plan to implement them. We need to ensure that our revenues and our staffing are sufficient to meet our needs before we embark upon any new initiative.

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And just to give you a picture of the World Federation of Hemophilia's finances, a Global Congress such as this is a very important event in the life of the Federation. It's the revenues from this Congress that actually help us to sustain programs over a two-year cycle. Unfortunately, after the Bangkok Congress we were faced with a very stark reality, not because the Bangkok Congress was not a huge success (in fact it was a great success for the World Federation of Hemophilia), but two events occurred around the time of the Bangkok Congress that made a significant difference. As you'll recall if you think back, there was tremendous change going on among the manufacturing industry, consolidation and realignment, which changed the pictures of the donors that were giving money to the WFH. But more importantly, a strengthening value of the Canadian dollar had a significant impact. Over the course of any year, about 80% of the revenues that the World Federation of Hemophilia receive come in American dollars. At the same time, about 80% of the money we spend is in Canadian dollars. The strength of the Canadian dollar against the U.S. dollar has resulted, over the last four years, in a loss of buying power of the World Federation of Hemophilia of about \$850,000. Thus, one of the first things I had to do after being elected in Bangkok was to work with the Board of Directors of the World Federation of Hemophilia to address this reality and we made the very difficult decision to decrease the budget of the World Federation of Hemophilia by fully one-quarter, 25 per cent, as you can see on this slide. However, what I'm pleased to report to you today as you can see the

subtle differences in the last two years, is that we are financially stronger and we are well positioned for the years ahead. We've made great progress in stabilizing our revenues, we've made great progress in working with our donors to make multi-year funding commitments, and I do believe that we are on the path to recovery financially. But let me tell you about a couple of our fundraising initiatives that we've embarked upon to help build upon this base.

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First, in 2005, the World Federation of Hemophilia launched our first ever global fundraising event. In 2005 we launched it as a pilot project and we received the generous support of our National Member Organizations in Australia, Ireland, New Zealand, and in the United Kingdom, and collectively those organizations helped us raise an additional \$32,000 to support our program work in achieving Treatment for All around the world. So this year, in 2006, because of the success that we had we are taking this program global and this will now be an annual fundraising event to support the work of the Federation and this means that this is diversified revenue, which is one of our important goals.

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Shortly after being elected president of the World Federation, I went out and visited with our corporate partners, our existing donors that have been so generous. It's quite easy for me to go back and ask them for more money each year. I do think we have a compelling case and they've been quite generous. But what I also asked them to do was to help us raise new money, to help us reach new markets, and to help us find opportunities to diversify the base. Not only so we don't have to go back to them to ask them for more money, but so that we can increase awareness and get others involved in our cause. So during this Congress we're announcing a new initiative and two companies actually took the challenge. Let me tell you about what they've done.

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First, today, we are announcing a new program called *Scoring for Care*. This program is going to be launched in the United States. Freddy Adu, who some of you may know that follow soccer, is a young soccer player in the United States. In fact, he was just rated as the most popular and known teen athlete in the United States. He has committed to join with the World Federation of Hemophilia to help raise awareness and funds to support our mission around the world. We're going to be piloting this program later this year with some of our chapters in the United States, and again, if successful, we see this becoming our second global fundraising event in the years ahead. I think this is a truly remarkable opportunity because Freddy comes from Ghana and he understands the difference between health care in developed and developing countries. And his message will be very effective as he talks about our needs to others. And I should also say that this program is made possible by the generous support of Wyeth and we really appreciate the work that they have done to come forward and help us diversify our base.

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A second initiative: for the first-time ever, the World Federation of Hemophilia is going to have a TV commercial, a public service announcement that we can use to communicate the message and the importance and the difficulty of living with hemophilia around the world. We already have commitment for this program to air on FOX News and on MSNBC and the CNN Airport Channel, networks that will be seen around the world. And we're going to use this program, this TV commercial, to reach out and educate people about hemophilia, hopefully bring them to our cause and hopefully raise some money. And if successful when we launch this pilot this year, we'll have full global distribution rights and perhaps in the future be able to tailor this program for use in other countries and other regions of the world. Together I see both of these initiatives as being extremely important and the kinds of things that we need to do more of in the years ahead, and so a special thank you to Wyeth and Bayer for stepping up and helping us achieve these goals.

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Our last theme is enhancing the structure of the WFH to achieve everything that we've achieved today.

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Certainly there's a lot of internal pieces that we need to do. We need to update our constitutional rules and organizational procedures. We need to strengthen our internal communications, and we're doing that with our National Member Organizations and with many of you. We need to implement succession planning throughout our volunteer structure as it grows to make sure that we don't run into a situation where someone leaves a country program and we don't have their talent and services or someone to follow in their shoes. And of course we're going to be doing some things to make sure that our talented staff in Montréal, upon which everything that we do relies, are well taken care of.

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But I want to tell you about one other initiative that we're launching at this Congress. For a number of years the World Federation of Hemophilia has had a medical advisory board. But our mission now is to make sure that this Medical Advisory Board is positioned to support all of the work of the World Federation of Hemophilia. So we're reorganizing that board. We're holding our first meeting during this Congress and we're going to bring together the chairs of each of our multi-disciplinary medical and scientific committees to work as a core team to help us plan and implement our workshops and our training programs as we move forward in the years ahead. And now that they've all grown and proven to be important parts of the World Federation in their own right, it's time that they come together to help us work and plan for the future. I see this as a great opportunity to further expand our work and support the work of healthcare providers in all regions of the world.

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As a global family, it is my hope that when we leave this meeting we all are united around a single vision of achieving Treatment for All. Thank you.