HIGHLIGHTS OF THE IDF SIDE EVENT TO THE 70TH WORLD HEALTH ASSEMBLY

Access to Diabetes Medicines and Care in Underserved Populations: Patient, Health Worker and Multilateral Perspectives on Policy

23rd May 2017, InterContinental Hotel (Geneva)
BACKGROUND

IDF launched the Blue Circle Voices (BCV) network in 2016 to bring to the fore the voice of People with Diabetes. By June 2017, the network comprised 103 members with all types of diabetes and of all ages from all around the world.

One of the network’s first activities was an online consultation which was designed to identify the network’s key concerns, challenges and priorities. Feedback from this consultation showed that access to diabetes care and medicines is the top priority of people living with diabetes across the world. Even access to insulin, a life-saving medicine that was discovered almost a hundred years ago, remains an issue for thousands of people around the world.

Some advances have been made in improving access to care since the WHO target on 80% access to essential medicines was agreed, but to achieve this target by 2025, urgent action is needed now. People living with diabetes have a key role to play in the development of new policies, and collaboration and discussion with the health authorities should be fostered.

OBJECTIVES OF THE IDF EVENT

Access to essential medicines and care will be one of the key diabetes-related topics for IDF in 2017 and the coming years. As we get closer to 2025, IDF aims to redouble its efforts in making essential diabetes care available and accessible for everyone.

IDF, with the support of Medtronic Foundation, convened this meeting with the specific aims of:

- **Raising awareness of the BCV network** and the role of people with diabetes as experts in helping address the challenge of access to essential diabetes medicines and care;

- **Highlighting the gaps** between theoretical provision and real availability of medicines, to inform discussion on what is needed to achieve the WHO 2025 target on 80% access to essential medicines;

- **Obtaining consensus between patients and frontline workers** on priority solutions to overcome the gaps.
Speakers

Prof Nam Han Cho  
IDF President-elect

Dr Etienne Krug  
Director of WHO’s Department for Management of NCDs, Disability, Violence and Injury Prevention

Ms Riva Greenberg  
Health coach and member of the IDF BCV network from the US

Panel session (moderated by Ms Paurvi Bhatt, Senior Director for Global Access, Medtronic Foundation)

Ms Samalie Kitooleko  
Nurse at the Ugandan Heart Institute

Ms Kwanele Asante  
Lawyer & Bioethicist, South Africa

Dr Sanele Madela  
Frontline Health worker, South Africa

Ms Vanessa Pirolo Vivancos  
Project Coordinator at the Associação de Diabetes Juvenil of Brazil and member of the IDF BCV network

Ms Stela Prgomelja  
Vice-President of the Serbian Diabetes Association and member of the IDF BCV network
**MEETING HIGHLIGHTS**

**Prof Nam Han Cho**

This event, which took place during the 70th World Health Assembly in Geneva, was hosted by IDF President-elect, **Prof Nam Han Cho**, who, in his opening remarks, reminded the audience of the current scale of the diabetes challenge worldwide: 415 million adults had diabetes in 2015 and one person dies of diabetes-related complications every six seconds. Prof Cho highlighted the fact that insufficient access to diabetes medicines and care leads to worse health outcomes and the potential development of severe complications. Prof Cho explained that IDF is committed to help improve access to diabetes care for everyone and presented the main highlights of the *Access To Medicines And Supplies For People With Diabetes – A Global Survey On Patients’ And Health Professionals’ Perspective*. This study was conducted with IDF’s Members in 2016. Its aim was to provide to policymakers, policy implementers and diabetes advocates worldwide with an accessible summary of the current data on availability, access and prices of medicines and supplies from the viewpoint of people with diabetes. It shows that while there is combined governmental and non-governmental provision of essential medicines in four of five high-income countries, this decreases to just one in five for low-income countries – not nearly where it should be. The participants in this study outlined the issues of major concern as being the lack of diabetes medication/supplies, the lack of education and limited access to medication.

“It is estimated that 5 million people died from diabetes worldwide in 2016, many of them due to lack of access to diabetes essential medicines”.

*Prof Cho*
MEETING HIGHLIGHTS

Dr Etienne Krug

Dr Krug started his intervention by stating that the vast majority of the 50 million of NCDs-related deaths last year could have been prevented, including the ones related to diabetes. He stressed the fact that in 2015 very few countries had made good progress in improving access to medicines; among the reasons behind this were a lack of political commitment resulting in limited national actions and funding, weak logistics structures beyond the health systems, as well as technological industries hindering advances instead of promoting them. WHO is currently launching a pilot programme that aims to make some of the more expensive cancer treatments more accessible to low-income communities. The initial focus is currently on cancer, with diabetes management potentially the focus of a later phase. Dr Krug’s final remarks emphasised the need for multilateral collaboration between governments, civil society organisations and the private sector to make a real difference.
Ms Riva Greenberg

Ms Riva Greenberg started her intervention with a presentation of the BCV network, whose members will be the eyes and ears of IDF on the ground. She highlighted the importance of peer education, which motivates and inspires people living with diabetes. She continued explaining that, despite being a rich country, the US is near the bottom of the list among advanced countries with regard to spending and healthcare. As an example, she cited glucose monitoring which was only added to Medicare coverage, and only conditionally, in March 2017. She also emphasised the need for a more relationship-centric approach to care, having patients and providers work collaboratively, to optimise results for both. Ms Greenberg also mentioned that, during her travels, she saw discrimination against people with diabetes even in high-income countries like Japan where the word “diabetes” is equated with “disturbed lifestyle.” She finalised her intervention by introducing videos from two BCV members from Costa Rica and Chile, who explained the access to care issues that they experienced in their respective countries.

“The quality of the provider-patient relationship can be as significant as access to, and affordability of, medicines”.

Ms Riva Greenberg
The discussion panel began with a brief introduction of Ms Paurvi Bhatt of each of the panellists.

**Ms Stela Prgomelja**

Ms Stela Prgomelja from Serbia indicated that access in her country is challenging, citing as examples that people with diabetes do not receive enough test strips, that there is a lack of endocrinologists for children and that modern therapy for the treatment of type 2 diabetes is not generally available. She also stated that the lack of engagement from governments results in people with diabetes trusting them less than patients’ networks such as the Blue Circle Voices, of which she is a member. She also reminded the audience that tackling diabetes should not be seen by governments as a cost, but as an investment.

**Ms Vanessa Pirolo Vivancos**

Ms Vanessa Pirolo Vivancos stressed that access to diabetes medicines has improved in Brazil over the last few years, although the economic crisis has severely hindered this process and medicines remain expensive – the inability to pay for treatment is a main issue in the country. She also encouraged people to bring the topic to their government and to work together to develop a training programme to better support the fight for better access.

**Ms Kwanele Asante**

Ms Kwanele Asante highlighted the fact that providing access to essential medicines to all who need them is a challenge despite the ongoing development of advanced drugs, in the field of cancer for example. She mentioned that fact that lack of equitable access to healthcare services is an issue in her country, South Africa, where only 18% of the population can afford private insurance and more than 75% of black South Africans are uninsured. Ms Asante stressed the need to eliminate key barriers to access to medicines such as high prices and excessive patent protections. She implored patients to hold their governments to account in relation to their United Nations right to health obligations, especially in relation to non-communicable diseases.
Ms Samalie Kitooleko

Ms Samalie Kitooleko, a nurse at the Uganda Heart Institute, indicated that people often suffer from more than one NCD and that she treats many people with diabetes complications. For Ms Kitooleko, one of the main issues is that even when medicines are accessible, they are often unaffordable for patients – who may also experience difficulties in safely storing them once purchased and in monitoring their glucose at home through lack of supplies and education. One key strategy to start addressing the issue was seen as ensuring that clinical services offer fully integrated care taking into account not just diabetes but also some associated complications and/or other diseases.

Dr Sanele Madela

Dr Sanele Madela indicated that knowledge and education is key to empowering people living with diseases and improving access to medicines. Many patients do not adhere to treatment when changing medication precisely because of a lack of information. He also suggested that medicines and care need to be taken to the people, as many of them cannot attend any health facilities, and that the challenge of having two distinct health systems – private and public – needs to be addressed to ensure better healthcare.

Final remarks

Ms Pragomelja and Ms Pirolo agreed that it is critical that all stakeholders sit at the same table and think about the next steps, with the same desire. Ms Asante expressed her wish for the private sector to come on board to improve access to medicines in underserved communities and low-income countries. Ms Kitooleko highlighted the need to improve access and availability of screening and proactive prevention, which could make a real difference. Dr Madela insisted on the need for suppliers to go to the patients, which would have a great impact on management.

In his final remarks, Prof Cho highlighted the need to collaborate with all stakeholders across the board to achieve the “three As”: availability, accessibility and affordability. He closed the session by reminding the audience that together we are stronger, we can do better, and we can make the world a better place for people with diabetes.
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