



Blue Circle Voices NEWSLETTER



OCTOBER 2017

NEWS FROM IDF

CALL FOR NEW MEMBERS

The <u>BCV network</u> now comprises 130 members from all over the world. The network has received overwhelming support from people with type 1 diabetes, who represent half the people in the network. At this point in time, in order to be more representative of the actual breakdown of the types of diabetes globally, we are looking to increase the number of members in the network living with other types of diabetes. We are thus launching a call for new members living with type 2 diabetes, having a history of GDM or living with another type of diabetes. If you know anyone that fulfils the criteria to be part of the BCV network, please contact us at <u>bluecirclevoices@idf.org</u> to let us know.

ADVOCACY TOOLKIT

In view of the <u>High Level Meeting on NCDs</u> that will take place in 2018, IDF will launch a global call to action. In order for its Members to join this call and develop their own national campaigns, IDF has prepared a toolkit, including detailed information on the context of the 2018 review and the best ways to join the campaign. IDF will develop a similar toolkit for the members of the BCV network, so that they can learn about this important political process and how they can support the call to action.

BCV CONSULTATIONS

Some 70 BCVs responded to the second consultation launched in June 2017. This consultation, focused on the barriers that the BCV network face when accessing diabetes care, medicines and supplies, showed that about three quarters of the BCV respondents have experienced at least one barrier to access, the main one of which was the affordability of medicines and care. Underlining the size of the challenges confronting people living with diabetes, all individual barriers tracked in the survey (except geographical accessibility) were each faced "always or frequently" by at least 20% of BCVs. A key conclusion was that governments are the critical stakeholders who need to take action to put in place the necessary framework to ensure improved access and better health outcomes. The full conclusions of the BCV consultation will be available on the IDF website in early November.

In mid-October, the third BCV consultation regarding patient-centred care was launched. This consultation will aim at understanding the views of the BCV network regarding the quality of care received since their diagnosis/ the diagnosis of the person they care for.

THE BCV FORUM

In October, IDF launched the BCV online Forum - a platform that will allow the BCV members to engage with each other in discussions on key diabetes topics. All BCV members have received an invitation to join this Forum, that will only be accessible to members of the network. IDF will shortly send all BCV members the instructions on how to post new discussions and how to engage in existing ones.



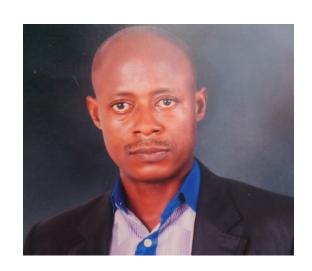
ADVOCACY
AWARENESS-RAISING
EDUCATION - PREVENTION

Bernard Matthias Enya (Nigeria)

Due to ongoing strikes in Nigeria leading to shortages of medical staff, many hospital patients have been discharged before they were fully recovered.

This situation is affecting people with diabetes and other patients alike. In order to draw attention to this urgent problem, Bernard has written a save our soul message to the Minister of Health in Nigeria, explaining the current situation and urging the government to take action.

His call has been relayed in the media and he is currently awaiting an answer from the government.



Liliana Tieri (Argentina)

On July 19 2017, Liliana Tieri, the founder of <u>CUI.D.AR</u> received the governor of the province of Buenos Aires, Maria Eugenia Vidal. This was made possible through the help of Estefania Malassisi, a member of the <u>Young Leaders in Diabetes</u> Programme and a young leader from the CUI.D.AR

association. By sending a letter to the governor explaining the situation of people living with diabetes in Argentina, Estefania was able to catch the governor's attention and encourage her to learn more about diabetes. During this meeting, Liliana and Estefania were able to provide details on the situation of the people living with diabetes, and the legislation that needs to be put in place to best address their needs. Liliana hopes that diabetes will now become an integral part of the governor's agenda.



Anne Coulibaly (Côte d'Ivoire)



On September 9 2017, Anne participated in a meeting on the preparation of World Diabetes Day. Anne, as the Interim President of the NGO, La maison du diabétique, coordinated the activities to prepare the practical organisation of their participation in WDD. During the meeting, they also looked at the remaining activities that need to be conducted in 2017 and started thinking of the Action Plan for 2018.

One of the main issues in Côte d'Ivoire is the lack of awareness of diabetes, as people are more focused on AIDS. To ensure that diabetes is discussed at both the local and national levels, Anne and her association have decided to keep visiting various villages to raise awareness and provide education.

Delphine Arduini (France)

From July 21 to August 5, Delphine organised the 5th T1D challenge. It consisted of five days of trekking in the Sierra Nevada and finished with the ascension of Mt Langley in California. The team that undertook this challenge consisted of 14 people with T1D and four doctors, coming from 10 different countries. Those challenges have been organised yearly since 2013 by Delphine through her organisation, World Diabetes Tour. This programme aims to inspire people living with T1D, connecting with them through a common physical activity and empowering them

by showing them that living with diabetes is, in no way, a barrier in their life. Delphine also participated in a <u>six-day trekking trip from August 26 to August 31 2017</u> around the Mont Blanc and across three countries. The team consisted of 12 people living with T1D and a doctor. This programme, Adventure



Team, was also organised through Delphine's organisation World Diabetes Tour with the same three objectives.

Carol Hendricks (South Africa)

On September 14, Carol, in collaboration with the <u>University of the Western Cape</u>, organised random blood glucose and blood pressure testing in a community shopping mall.

Around 150 people were screened and received information on diabetes, raising their awareness of the disease.



Bernard Matthias Envia (Nigeria)

On August 23 and 24, the World <u>Diabetes Foundation's</u> partners and stakeholders from Nigeria met to participate in an event Strategies for organised by **Improving Diabetes Care in Nigeria** - SIDCAIN in partnership with the Federal Ministry of Health. The theme was "DIABETES and NCDs in NIGERIA - Perspectives, Challenges and the way forward". The Federal government, civil society organisations healthcare experts from various organisations such as WHO, World Diabetes Foundation, the Diabetes Association of Nigeria, NCD

Alliance and many others attended the event. The goals of this event were to raise awareness among major stakeholders on the need to improve NCDs and diabetes care in Nigeria; to highlight existing projects and foster further cooperation between relevant stakeholders; and finally, to inspire state and federal authorities to take leadership and commit to improving NCDs and diabetes care in Nigeria. During this event, Bernard made a presentation during the plenary, and afterwards gave interviews to show the perspective and narrate the burden, suffered by people living with diabetes due to discrimination and insufficient health coverage by the National Health Insurance Scheme Policy. You can access one of the interviews here.



Bernard also addressed a few recommendations to the relevant stakeholders that participated in the meeting, restating the need to ensure better coordination between the various health services, ensure access to all essential medicines and allow for greater involvement of the people living with diabetes in their diabetes management and care.

Bruno Helman (Brazil)



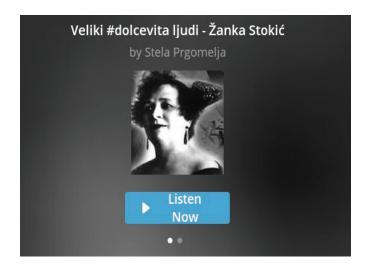
To raise money to sponsor JDRF's clinical research towards finding a cure for diabetes, Bruno has started a campaign called #42FOR420MILLION. You can access his campaign website and campaign video. He will run the TCS New York City Marathon (42 km) on November 3, for the world's diabetes population. Running this marathon will allow him to raise money for, and awareness of, diabetes, while also showing that people living with diabetes are able to achieve what they want if they have the right attitude and respect their health.

Stela Prgomelja (Serbia)

Stela has started a short radio show (each show being seven to eight minutes' long) in which she discusses famous people in Serbia who lived or are currently living with diabetes. This show, named "Big #dolcevita people" focuses on actors, writers, sportsmen/women, politicians and their lives with diabetes, their relation to therapy and the lifestyle they had to adopt.

Audience for the show has been good to date, as people living with diabetes relate to it and feel inspired by what those famous people were able to achieve while living with diabetes. The show demonstrates that living with diabetes should not prevent you from following your dreams and achieving great things.

Programmes are uploaded on Mixcloud, Soundcloud and shared on Facebook pages and groups. Stela is currently considering producing the same shows in English to reach a wider audience. You can access the recordings of the show on the following link.



Rakiya Kilgori (Nigeria)

In early September, an outreach event was organised by Rakiya in the Kilgori district. During this event, screening took place while at the same time, doctors provided general education on diabetes. They discussed the complications that could occur if diabetes was not diagnosed early and treated in an adapted way. The media was present and interviewed Rakiya and other people participating in the outreach event.



Basem Futa (Saudi Arabia)

On July 1, Dr Basem Futa and a diabetic care team of the Saudi Diabetes and Endocrine Association worked jointly to host an educational and interactive gathering of students living with diabetes, their families and schoolteachers.

The purpose of this gathering was to educate teachers on the best ways to deal with students with diabetes, providing information to them on their health requirements.



Students with diabetes were also encouraged during this event to maintain their blood sugar at a normal level, eat healthy food, perform regular activities and adopt a healthy lifestyle to promote their health and wellbeing both now and in the future.

Dr Basem Futa, as both a member of the organising committee and a speaker, gave lectures on diabetes education, hypo and hyperglycaemia management, exercise and healthy eating.

Weronika Kowalska (Poland)



As part of the preparation for World Diabetes Day, which takes place every November 14, <u>IDF Europe</u> organised an exhibition with a blood sugar testing booth in Brussels in the <u>European Committee of the</u> Regions (CoR) offices on September 26.

The event was designed to raise awareness of the need for diabetes prevention among policy makers and CoR staff acrossEurope. Weronika was actively involved in the preparation of this exhibition, designing the concept, the materials and installations. This event was a big success, with additional MEPs and MPs signing the Diabetes Pledge document, a document launched by IDF Europe at the time of the last European

elections which can be signed by policymakers to show their commitment to the diabetes cause. The names of the policymakers who signed the pledge can be found here.

Aisha Indo Lawal (Nigeria)

In July and August 2017, Aisha was actively involved in raising awareness of diabetes by setting community outreach up programme. Together with the Diabetes Association of Nigeria Katsina Chapter and the Institute for Dietetic Association of Nigeria State Chapter, Katsina Aisha travelled to several cities to educate the general population diabetes prevention on treatment and to put a stop to the discrimination of people with diabetes. Over 3,000 participants took part in those events and were screened for diabetes. These event were very useful as they allowed

the discovery of undiagnosed cases of diabetes. In collaboration with the Diabetes Association of Nigeria Katsina State Chapter and <u>Insulin for Life USA</u>, Aisha also distributed free insulin to 200



patients living with type 1 diabetes in two hospitals of the region. This was done to support people living with diabetes, especially children who cannot afford to buy insulin.



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