



Blue Circle Voices

The global voice of people living with diabetes



News from the
BCV members

IDF side event to the
70th World Health Assembly



BCV first consultation:
The priorities of
the network



Policy recommendations
to improve diabetes care in **Brazil**
and **South Africa**



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IDF side event to the 70th World Health Assembly

On 23 May 2017, on the occasion of the 70th World Health Assembly, IDF held a panel discussion in Geneva between people with diabetes and healthcare professionals on priority solutions to overcome national gaps between provision and availability of diabetes care and treatment among underserved populations.

The event highlighted the central role of people with diabetes in all aspects of diabetes management, care and prevention and introduced our new network, [the Blue Circle Voices](#), who was represented by three of its members: Riva Greenberg from the US, Stela Prgomelja from Serbia and Vanessa Pirollo Vivancos from

Brazil.

To learn more about the event, please download the IDF highlights report (only available in English) on this [link](#). You can also read the entries that BCVs Riva and Vanessa wrote on the event in, respectively, the [Huffington Post](#) and [Saúde \(the main online health magazine in Brazil\)](#).

BCV first consultation: The priorities of the network

In December 2016, IDF held a consultation with the BCV network with the objective of establishing the priorities of the network. Some 82 participants from 43 different countries responded to the survey. The main issue identified by the BCV members was access and

affordability of medicines, devices and medical care, followed by education, prevention and finally discrimination. You can learn more about the priorities of the BCV network by downloading the highlights report [here](#).



Policy recommendations to improve diabetes care in Brazil and South Africa

Over the last few months, IDF has been working with its Members and BCVs from Brazil and South Africa in developing country-specific policy recommendations to improve access to diabetes care. IDF is now working with Brazilian and South African BCVs to explore ways to effectively disseminate

these recommendations. We are also developing similar policy recommendations for India, China and Russia, with the objective of promoting them with the support of the IDF and BCV members during the [9th BRICS Leaders' Summit](#) that will take place in China from 3 to 5 September 2017.

We will keep you informed of the progress in the next newsletter. Meanwhile, you can read the policy recommendations on these links: [Brazil \(English\)](#), [Brazil \(Portuguese\)](#), [South Africa \(English\)](#).

BCV section on IDF website

In April 2017 IDF launched its new website, with a new and fresher design and brand new sections – such as the BCV. In the “[Meet the Blue Circle Voices](#)” section you can read the BCVs’ public profiles. On the “[Testimonies](#)” section you will regularly find new stories and videos from the BCVs. There is also an “[Activities](#)” section, where we will report on the activities that IDF undertakes with the BCVs, as well as a “[Consultations](#)” one, which will include the highlights

of each consultation with the network. A “[Become a BCV](#)” section has also been created, so

that anyone interested in joining this interactive community can learn how to do it.



Advocacy



From left to right: Bruno Helman, Ricardo Barros, Vanessa Pirolo Vivancos, Marcos Fireman and Francisco de Assis

Bruno Helman and Vanessa Pirolo Vivancos from Brazil

On 31 May, BCVs Bruno and Vanessa had a meeting with Mr Ricardo Barros, Health Minister of Brazil, during the conference Brazil Invest 2017 in Sao Paolo. The conversation focused on the shortage of basic supplies (needles, test strips, syringes)

and medicines (NPH and regular insulin) and the need to create a national education program for healthcare professionals to better assist people with diabetes in the country. Vanessa and Bruno also requested more clarity about the timeframe for the government to

start providing insulin analogues and who will be covered by the protocol that was approved in February 2017.

Vanessa and Bruno will soon have a follow-up meeting with Mr Francisco de Assis, Head of the Health Attention Secretary.

Sheila Regina de Vasconcellos from Brazil

As Vice-President of ADILA (Associação dos Diabéticos da Lagoa), a patient organisation advocating for an end to the shortage of diabetes medication and supplies in the Rio de Janeiro State, Sheila was involved in several activities, including the organisation of a gathering of over 50 people in front of the office of the Health Secretary of Rio de Janeiro on 31 May 2017, to protest against the lack of provision of insulin, test strips, syringes and other supplies for over five months now. You can follow the activities of ADILA on its [Facebook page](#).



(Sheila and fellow protesters at the concentration in front of the office Rio de Janeiro's Health Secretary)

Over the last few months, Sheila has also written several articles in [her blog](#) and promoted lectures

on motivation, self-management and diabetes and carbohydrate counting.



(Aisha, in green, meeting with HE Governor of Katsina, in blue).

Aisha Indo Lawal from Nigeria

On 15-16 February 2017 Aisha and the [Diabetes Association of Nigeria](#) organised an advocacy meeting with the Emir of Katsina, the Emir of Daura and community leaders

to discuss how they could support the Diabetes Association of Nigeria and the people with diabetes in the region. Aisha presented the BCV network and the community

leaders committed to developing a similar initiative at the local level.

Nathália Noschese from Brazil

Nathália, who is also an IDF Young Leader, created [Piquenique Azul](#) (Blue Picnic) in 2016 with the objective of bringing people together and offering a pleasant day full of different experiences, while raising awareness about diabetes. The picnic always takes place in the Villa Lobos Park of Sao Paulo and focuses each time on a different topic.

Piquenique Azul is supported by a team of 12 volunteers. The 6th and so far last edition of this event took place on 25 June 2017 and focused on the [DiAthlete Global Tour](#), the project created by the former IDF Young Leader Gavin Griffiths (UK) to promote the benefits of physical activity for young people with diabetes.

Piquenique Azul has become a great success, growing from 30 attendants in the first edition to more than 400 in the last one. Future editions of Piquenique Azul will take place in Rio de Janeiro and Minas Gerais, which will allow Nathália to bring even more people together. We will continue informing you about this successful project in future newsletters!



(Gavin Griffiths and Nathália Noschese at the latest edition of Piquenique Azul)



Frédéric Paliwoda from France

From 24 to 29 May 2017, Frédéric participated in [Explore Corsica](#), a five-day memorable bike adventure of 420 km in Corsica (France), organised by Le Tour de France. Frédéric, who rode along professional cyclists such as Cadel Evans, Frank Schleck and Antoine Dénériaz, undertook this challenge to show that diabetes does not prevent you from realising your dreams and to promote physical activity among people with diabetes. You can learn more about Frédéric's experience in his [Youtube videoblog](#) and on his [website](#).

On 15 June 2017, Frédéric was invited to participate in one stage (88km between Cahors and Figeac) of the Tour organised by the [Randonnée Cycliste du Diabete](#). At the finish line, screening, awareness and prevention activities were organised for the audience. A very good occasion to speak about the role of sport in preventing type 2 and managing all types of diabetes!

Stela Prgomelja from Serbia

Stela is the Vice-President of the [Diabetes Association of Serbia](#) and on 21 June 2017 she organised a football match between the team of the Association and the Serbian Military Airforce team. The objective of this activity was to show that diabetes and sports go together and that people with diabetes can do everything. Several media outlets covered the match and Stela was interviewed on TV.

This activity motivated some young people with diabetes to join the Association's football team. There was also the opportunity to discuss the diet of the Airforce members, who explained their healthy choices and gave their full support to the activity participants.

Aisha Indo Lawal from Nigeria

In 7 March 2017 Aisha and the [Diabetes Association of Nigeria](#) organised an event to launch the first book on the management of diabetes in Hausa language. This occasion was used to seek support from the Government and was attended by high-level representatives of the Katsina State, including the Deputy Governor, the Secretary of State and the Emir.

In June, Aisha led an awareness campaign on

the occasion of Ramadan, consisting of a TV and radio programme, a one-day workshop to healthcare professionals, community meetings and the distribution of the [IDF and DAR Diabetes and Ramadan: Practical Guidelines](#). The objective was to ensure the optimal care of people with diabetes that fast during Ramadan.

Stefano Turra from Italy

On Sunday 2 April 2017, the 1st International Marathon for Athletes with Diabetes was held in Rome, in collaboration with the 23rd Marathon of Rome. The event was organised by [ANIAD](#), and Stefano was responsible for coordinating the attendance of some of the



athletes.

The event was a great success and proved that sport is a great way to handle diabetes and to know oneself.

Julie Seow from Singapore

In 2016, Chiara Riccardi, a 27-year-old Type 1 on an insulin pump and her boyfriend Riccardo conceived a project called '[For a piece of cake](#)'. They travelled a distance of 18,000 km from Italy to Singapore by bicycle to show that diabetes should never stop our dreams. They crossed 21 countries and Chiara enjoyed a piece of cake at each stop!

On their arrival to Singapore on 29 June 2017, Julie and [TOUCH Diabetes Support](#) (TDS) organised a



reception at a cake shop. On July 1, they also coordinated a session with a diabetes group where they shared their incredible journey. This was a great way to champion physical exercise and adventure learning experiences for the

young people with diabetes of her association, as it shows that people with diabetes can pursue their passions and live a fulfilling life!

Betsy Ray from the US

In 2011 Betsy founded the non-profit organisation [Diabetes Activist](#), aimed at assisting people with Diabetes to maintain optimal health, educating them about how to navigate both the nature and the environment of diabetes and teaching them how to challenge the current paradigms to gain positive outcomes while utilising options that provide optimal positive results and do no harm.

In January 2017 Betsy recorded a TEDx Talk, which was published online on March 7. The talk, titled "Diabetes: destroying the myths", can be watched [here](#).

Betsy highlighted a problem that is affecting every single person with diabetes: stigma and requested that people are educated on diabetes, and not on the myths that surrounded it.



Liliana Tieri from Argentina

[CUI.D.AR](#), the association that Liliana founded many years ago, has organised several very successful activities with young people with diabetes and their relatives between March and June 2017. These included the participation of 30 volunteers of CUI.D.AR in the Buenos Aires Ironman, several workshops in nutrition (cooking lessons, carbohydrates counting) and a masterclass on new technologies to improve diabetes management. You can learn more about CUI.D.AR activities on their [Facebook page](#).



(left: cooking lessons from children with T1D; right: Buenos Aires Ironman)

Qi Zhang from China

On 21 May 2017 BCV Qi Zhang, a paediatrician from Beijing, organised a workshop in the offices of the diabetes association with which she collaborates to explore new treatment models for type 1 diabetes, discuss patient self-management and talk about peer support and doctor-patient communication platforms.

Thirty peers attended this workshop, in which a 13-year-old-girl with diabetes and her mother explained how they had changed the perception of diabetes inside their own family. The activity was a success and will be replicated in Tianjin, Shanghai and Changsha.

Roxana Vizcaíno from Ecuador

On 17 June 2017 Roxana was in charge of the photo production of the [FUVIDA Foundation's](#) latest initiative to raise awareness about type 1 diabetes. The objective of the project is to provide children with diabetes education, so they are empowered to effectively manage their condition. This is done through involving the

children in activities specially designed for them – in this case, a Star Wars roleplay in which children with diabetes become Jedi Knights that teach the bad guys about proper diabetes management.



Bernard Enyia from Nigeria

The Blessed Tansi Parish Ogbatai Woji Community of Port Hartcourt regularly organises a 15-20 kilometres walk, named "Walking with Christ", so the members of the community and their relatives engage in physical exercise at least one day per month. On 29 April, Bernard took part in this activity by conducting free blood sugar screenings, eye checks, and lectures on diabetes, hypertension and eye health. He shared with



(Some of the participants after the road walk)

the audience his nine years' experience of living with diabetes and promoted some educational materials, including the poems

the he writes to demystify diabetes in his country.

THE DIABETES BEATTITUDES

Composed By: Comrade Bernard Enyia, Blue Circle Voice member from Nigeria

Blessed are those who have excessive thirst for water because of diabetes for they shall drink plenty of water daily.

Blessed are you when you are angry and depressed because of diabetes for you shall be comforted

Blessed are those who hunger amidst plenty for they shall see a dietician

Blessed are those who experience blurred vision for they shall see the ophthalmologist

Blessed are the young with type 1 diabetes for they shall see a consultant Endocrinologist

Blessed are you when you are exposed to diabetes complications such as stroke, heart failure, infertility, Retinopathy and amputation for yours is the kingdom of heaven

Blessed are you when your doctor prescribe all manner of drugs for your wellbeing be ready and willing to visit a pharmacy shop

Blessed are you when you are obese for you shall embark on physical exercise

Blessed are you when you experience hyper and hypoglycemia for you shall obtain a Glucometer

Blessed are you when you are overweight for you shall check your Body Mass Index (BMI)

Blessed are you when your family and friends reject you and the government is not doing anything to ameliorate your burden as a diabetic, rejoice and pray to God for your reward is greater in heaven

Blessed are you when you spend above 50% your income on drugs for the sake of diabetes, be glad and ready to join the Diabetes Association of Nigeria.

Blessed are you when IDF recognised your volunteer effort and sacrifices on local activities of diabetes care be glad and ready to join the BCV

(One of Bernard's poems)

Rakiya Kilgori from Nigeria

On 19 June 2017 Rakiya and the [Diabetes Association of Nigeria](#) - Sokoto State Chapter, organised the event "Footcare and diabetes" to raise awareness on the need of keep the feet healthy and maintain good blood glucose control. Rakiya spoke about the diet-related aspect of this and also shared the work that IDF and the BCV network members are doing around the world.

On the occasion of Ramadan, Rakiya was also involved in some other activities, such as fundraising for people with diabetes from underserved populations, and the organisation of a lecture about fasting and diabetes accompanied by free blood glucose screening, which was attended by more than 700 people.

Kawtar Belkhadir from Morocco

Kawtar was part of the organisation committee of a national colloquium that took place in Rabat on 7-8 July 2017. This scientific event allowed attendees to learn about the latest updates on diabetes management. National and international experts participated.

In her role as an ophthalmologist, Kawtar has also started to volunteer at the Mohammed V Foundation, where each week she has consultations with children with diabetes and follow their complications, with the objective to improve their access to care.



(Kawtar, in the middle, with some of the attendees to the colloquium)

Basem Futa from Saudi Arabia

Dr Basem Futa collaborates closely with the [Saudi Diabetes and Endocrine Association](#) (SDEA), of whose Scientific Committee he is member. As such, he participates in many activities to educate people about healthy lifestyles, including safely and healthily fasting during Ramadan. On 27-28 May 2017, an educational activity took place in Al-Khobar City, which several hundreds of people attended – including not

only people with diabetes, but their relatives and friends.

Basem participated as a speaker in several sessions to explain to the audience how to effectively self-manage diabetes during the fasting days. He was also involved in the development of recipes of healthier versions of traditional dishes, which were



(Education session run by Dr Futa during the SDEA Conference)

distributed to the attendees during the conference. Another educational material shared with the participants was the [Fasting Guide developed by SDEA](#).

Perseus Prospere from Santa Lucia

Perseus is the Vice-President of the St Lucia Youth Diabetes Group and gets involved in many educational activities with the young people of his association. On 18 April 2017, he coordinated a workshop for newly diagnosed

people between the ages of 8 and 16, where he mentored the children on diabetes self-management and the importance of exercise. This activity was an important social occasion for them, as it helped them realise that many other

people have diabetes.

The experience was very satisfying and showed the need for more diabetes education.

You can watch a video of this activity [here](#).

Pablo Silva from Brazil

Pablo is part of the team of five people with diabetes (including BCV Sheila Regina de Vasconcellos), one journalist and one endocrinologist from Brazil that have founded the electronic magazine [Em Diabetes](#). This independent project is in fundraising phase, but a special article on Mothers' Day was already published in May 2017.

Pablo is responsible for content development. Em-Diabetes intends to be an information and training platform for patients and a place where they can be heard. You can learn more about Em Diabetes on the project's [Facebook page](#).

Riva Greenberg from US

On May 10 2017 Riva participated in a full day workshop organised by the [Patient Revolution](#) group with the [Columbia University Journalism School](#). Thirty-five people participated and were charged with the task of designing simulations to help empower patients and providers in empathetic care.

Riva and her group designed a game and an app to, in the long-run, create a nation of caregivers, taking into account the growing problematic of social isolation in the US.



(Riva presenting her group's idea at the workshop)

IDF forthcoming activities

Expanding the BCV network

The BCV network currently comprises 103 members from all over the world – [here](#) you can download a PDF that describes the structure of the network. More than half the people in the network have type 1 diabetes – we are really happy to count so many engaged people from the type 1 community!

At this point in time, we would like to increase the number of people living with other types of diabetes in the network. With that objective, we have launched a call to all IDF Members to nominate new enthusiastic people that would like to become BCV members.

If you know someone that fulfils the [criteria](#) to be part of the BCV

network and has type 2, a history of GDM or a less common types of diabetes, please contact us at bluecirclevoices@idf.org to let us know.

IDF campaign on the occasion of the UN High Level Review on NCDs 2018

In 2018 the UN will be reviewing the country progress to achieve the targets all nations unanimously agreed to in 2012, including a 0% increase in diabetes and obesity prevalence, and 80% access to essential NCD medicines and devices by 2025. This [high-level](#)

[meeting](#) is key for IDF and the whole NCD community, so we will undertake a year-long campaign in order to highlight the need for urgent government action if we are to achieve those objectives.

IDF is currently working on a toolkit that will allow its Members

and BCV network to advocate towards their governments for stronger actions on diabetes. You will very soon receive more information about this.