Improved Weekly Updates

We have carefully analysed and considered your comments to the 2019 Views of the network consultation. Thanks to them, and to you, we have worked on improving the following weekly updates aspects:

- **The design:** the weekly updates have been entirely redesigned to a more modern version that adapts optimally to all your electronic devices: computers, tablets and smartphones

- **The length and relevance:** to make sure you only receive the most relevant information, we will limit the news to a few items each week

- **The engagement:** because it is not always obvious how to get involved, all the actions you can take part in will now only be one click away (blue button=chance to engage)

Thanks to your feedback, we now know that two out of three BCV members always read the Weekly updates. You believe this feature is essential in our communication – and we think so too.

We hope you enjoy your brand new and improved user experience!
What was your first thought when you were diagnosed with diabetes?

My first thought when I was diagnosed was a mix of different emotions. Luckily, I had my dad with me to make me feel safe. However, I remember I was a little bit worried and nervous about what was going to happen next. Was I going to die?

Had you ever heard about diabetes before your diagnosis?

I had never heard about diabetes before. I knew there was a disease that had to do with injections and food, and that elderly and overweight people had it, but I did not know it was diabetes.

What is the biggest challenge you have faced since you live with diabetes? How have you overcome it?

I do not see my diabetes as a challenge; life is a challenge no matter what. Diabetes comes with lots of responsibilities and there will be times more difficult than others. Personally, I have learned from my mistakes and see life in general as a lesson. The biggest challenge I have faced, and still currently face, is the lack of awareness about diabetes among the general population.

Is diabetes one of the reasons why you became an influencer? Would you say that sharing your story about diabetes has helped you manage it better?

Yes, 100%! I think sharing my story has helped others manage their diabetes in a more positive way. Currently, I talk about my experience with diabetes and eating disorders, which I know many people living with type 1 diabetes fear. Food is a central part of a person with diabetes everyday life and it is very easy to fall into an unhealthy relationship with it. That is why it is so important to talk about this topic: to understand the impact of our food choices and build healthy habits.

What do you think is the biggest diabetes challenge in your country?

The biggest diabetes challenge in Sweden is asking for help. If we fear we have a problem, we need to ask for advice and help one another, within the diabetes community and to our doctors. I know that many people in Sweden are ashamed of their diabetes. I believe we need to change that!

Why have you decided to join the Blue Circle Voices network?

I have chosen to join Blue Circle Voices because this network is doing an amazing job. It connects people from all around the world and allows them to share their experience! We need to connect and talk to each other more. Social media and networking together will make us feel less alone.
INTERVIEW WITH A BCV MEMBER

Osarenkhoe Ethel
Chima-Nwogwugwu (Nigeria)

What was your first thought when you were diagnosed with Gestational diabetes (GDM)?

My first thought was “What is gestational diabetes?”. Fortunately, my doctor immediately provided me with information about GDM, which encouraged me to read more on the topic. Thanks to this, I knew my baby and I were going to be okay.

Had you ever heard about diabetes before your diagnosis?

Yes, I had. Back then, I was a carer for my late mother and father, who lived with diabetes.

Years after your GDM diagnosis, you were diagnosed with type 2 diabetes. Do you notice a big difference between living with GDM and type 2 diabetes?

Of course, I noticed a huge difference. GDM was a temporary condition due to pregnancy. After giving birth, you can usually stop your treatment and your glucose level returns to normal. You also have fewer restrictions in your everyday life. On the other hand, type 2 diabetes is a condition that changes your life in the long term. You need to ensure your glucose level is under control to avoid complications, your medical expenses increase and so does your risk of developing complications. For me, type 2 diabetes is definitely more difficult to manage.

What is the biggest challenge you have faced since you live with diabetes? How have you overcome it?

My biggest challenge is ensuring a regular supply of medication, insulin and test strips. Sometimes, even if I have the money to afford them, they are not accessible. I am overcoming this challenge by staying in touch with the pharmaceutical representatives who are in charge of importing insulin and test strips. My tight links to them allow me to have access to my essential diabetes care at all times.

Has diabetes had a positive impact in your life?

Living with diabetes, regardless of the type, has made me a better person. I actively encourage healthy lifestyles, including healthy diets and regular physical exercise, to my family, friends and community. I became a diabetes advocate to empower people to overcome their fear of non-communicable diseases.

What do you think is the biggest diabetes challenge in your country?

The biggest diabetes challenge in Nigeria is the government’s lack of engagement. The government does not implement policies to support people with diabetes and their families, to ensure access to diabetes care, and to protect people living with diabetes. We lack the support of our government, at all levels.

Why have you decided to join the Blue Circle Voices network?

I joined the BCV network to join the effort of making the voices of people living with diabetes all over the world heard. I also wanted to learn more about diabetes, to feel more educated and empowered, and to share ideas with the rest of the world so that I can improve the situation of people with diabetes in Nigeria. I am grateful for this opportunity to share my experience.
Estefanía Malassisi (Argentina)

In end of April and beginning of May, Estefanía attended a series of advocacy meetings with Argentinian senators organised by her diabetes association, CUI.D.AR, in Buenos Aires. Other CUI.D.AR collaborators such as YLD member Violeta Houlton and Pilar Arrossagaray also participated in the activity.

The objective was to create awareness around type 1 diabetes and give it more visibility, which Estefanía believes it is lacking in Argentina. Her role was to act as a point of contact for future collaborations between CUI.D.AR and the Senate. Estefanía and her team managed to meet all Senate representatives and obtained very positive feedback to this initiative. She also presented the BCV and the YLD network to the senators.

Betsy Rodriguez (USA)

From April 14-17, Betsy spoke at a conference organised by the National Association of Community Health Workers (CHW) in Las Vegas (Nevada), to celebrate the 20th anniversary of the National Conference For and About Community Health Workers and launch the National Association of CHWs.

CHW are frontline health personnel who typically come from the communities they serve. The objective of this event was to unify the voice of CHW and to strengthen the profession's capacity to promote healthy communities.

Betsy organised a plenary meeting on Key Learnings for States and Policymakers from the Centers for Disease Control's Division of Diabetes Translation CHW forum. Over 1,000 people attended the event. Betsy was able to mention the BCV network as she talked about the opportunity for CHWs to be advocates for people with diabetes.
AWARENESS-RAISING

Betsy Rodriguez (USA)

Betsy kept up her involvement in diabetes activities by writing a blog post titled “Benefits of Including Community Health Workers (CHWs) on the Diabetes Care Team”. The post talked about how people of ethnic or racial minorities experience a disproportionate burden of disease and complications, and why interventions that effectively reach underserved communities are especially important.

Betsy explained that the engagement of CHWs as a workforce is a proven strategy for improving diabetes outcomes. CHWs typically work in their own communities, share cultural, economic, linguistic and other characteristics with the people they serve, and are able to build close, trusting relationships with communities.

Christine Maalouf (Lebanon)

On May 14, as part of DiaLeb’s programme “Diabetes in the Classroom”, Christine organised and talked in a school awareness session at the Collège des Soeurs des Saints Coeurs in Baouchrieh. She introduced students to DiaLeb’s mission, objectives and activities. The session included facts and statistics about diabetes.

It also focused on the importance of volunteering and verifying the source of information in order to access reliable information about diabetes. About 100 students were present and engaged with the session by asking questions and even inquiring about volunteering with DiaLeb in the future. All in all it was a success.
Chimezie Udochukwu Anyiam (Nigeria)

On April 9, Chimezie attended an event hosted by the Diabetes Association of Nigeria and World Diabetes Foundation in Owerri (Imo State), to promote the Diabetes Awareness and Care (DAC) project — a collaboration between the aforementioned organisations, which aims to take diabetes education and advocacy to every rural area in Nigeria. The project has kicked off in the States of Federal Capital Territory and Imo State.

The event targeted everyone living in Imo State and over 400 people attended. The objective was to make people aware of the rising incidence of diabetes, how to identify the symptoms and best practices in diabetes management.

Chimezie has the opportunity to talk about the BCV network to some the attendees.

Narsimha Raju Dichpally (India)

On April 27-28, Narsimha participated in the organisation of a Diabetes Awareness and Detection Camp, where he also acted as speaker.

This activity was carried out by Lions Club International in Hyderabad, India. Narsimha distributed pamphlets about diabetes awareness, presented the BCV network and talked about future plans on diabetes awareness in the region.

From July 2018 until today, Narsimha and his Club have conducted more than 660 camps, with around 179,000 people having benefitted from his services.

Most of the 800 participants in the camp were people living with diabetes or diagnosed with impaired glucose tolerance, and around 300 of them got a health check-up.
Osarenkho E. Chima-Nwogwugwu (Nigeria)

On April 19, in Lagos, Osarenkho volunteered with a medical team as part of an outreach programme organised by the Redeemed Christian Church of God in Gbagada. This activity is organised every Good Friday to offer free medical services to the community, aiming to reach people with undiagnosed diabetes, unmanaged blood pressure and other illnesses. People who are diagnosed are given free medication and a referral letter to the nearest government hospital for a follow up.

Osarenkho screened attendees’ blood glucose and blood pressure levels, provided them with information on those topics and answered their questions. Around 300 people attended the event.

On May 9, the Diabetes Association of Nigeria and Osarenkho organised an event in Lagos, in which she acted as speaker and moderator. The event brought together people with diabetes, carers, relatives, healthcare providers and stakeholders in diabetes to discuss how to empower and support people with diabetes in their everyday life. The conversation revolved around healthy lifestyles, exercise, and sharing personal stories on the challenges and successes of living with diabetes.

Around 30 people attended the event. Osarenkho took the opportunity to talk about the BCV network and stress its importance and impact on global health issues.

Rakiya Garba Kilgari (Nigeria)

On May 8, in Sokoto, Rakiya presented an event organised by the Diabetes Association of Nigeria. The main aim was to discuss Ramadan fasting and its effects on diabetes. The event also provided an opportunity to discuss how to avoid hyperglycaemias, especially in hot weather and due to high intakes of food and drinks, and how to recognise hypoglycaemia symptoms.

Rakiya advised people with diabetes not to fast unless they are aware of the dangers to their health. A team of doctors attended the event to speak about the topics and answer questions from the public. Rakiya spoke about the importance of exercise and a local diet with low glycaemic index foods. She also spoke about the BCV network in a bid to create awareness about the new trends to fight against diabetes.
On March 17, Amjad organised a one day event with AIMS Pakistan in Peshawar. The event was a Continuing Medical Education (CME) on diabetes for general practitioners and doctors working in the community. A total of 120 doctors attended the workshop.

Amjad talked about fundraising events, and how doctors can get involved in them. All attendees engaged and participated in the activity, and committed to provide better diabetes complications information to their patients to improve their prevention.

Amjad learned from this event that this type of activities need to be organised regularly in order to be efficient. Next time, attendees will be invited to share their views and experiences of living with diabetes and complications.

On May 14 in Katsina, Nigeria, Aisha led a two-day workshop on nutritional management of diabetes during the month of Ramadan. It was organised by the Diabetes Association of Nigeria Katsina State Chapter and the Association of Nigerian Dietitians Katsina State Chapter.

The workshop targeted healthcare professionals working in an endocrinology department and 50 of them attended. This objective was to improve and maintain the health of people living with diabetes during fasting.
On May 11, in Buenos Aires, CUI.D.AR diabetes association organised an event to present the 5th edition of “Young Leaders of CUI.D.AR”. Liliana, Executive Director of CUI.D.AR, funded this programme to train young people with type 1 diabetes to better manage their diabetes and prepare them to enter the job market, particularly to take on leadership roles.

On this occasion, Liliana spoke about how CUI.D.AR was funded and the work they do within it. She also tried to make attendees realise of their potential as leaders who can carry out actions that will raise the voice of people living with diabetes.

The event brought together people with type 1 diabetes and saw them interacting with each other and being motivated to learn. Some of the attendees were meeting other young people with diabetes for the first time, which made of this event a very special occasion.

Estefanía Malassisi (BCV and YLD member) and Lucas San Pedro (YLD member) participated as speakers to share with the new CUI.D.AR young leaders their experience on how to create and implement projects, and motivate them to launch their own. Estefanía and Pedro learned from this experience the importance of offering first hand experiences, both positive and negative, to young leaders.

On April 15, Liliana organised a CUI.D.AR training session on diabetes for school teachers in Buenos Aires, as part of the “Diabetes goes to school” initiative.

Since it was launched in 2003, this ongoing initiative aims to increase the teacher’s knowledge on type 1 diabetes so they can better help their students who live with it. Since its inception, the programme has educated more than 8,000 teacher and has created safer spaces for kids with diabetes.
On May 10, Vida spoke at an activity organised by Gabric diabetes education association in Tehran. The objective was to promote physical activity and show the general public that people living with diabetes can live like other people. The initiative also meant to raise awareness about diabetes to people who are unfamiliar with it and present Gabric.

Vida, alongside other volunteers from Gabric, took to the streets to hand out brochures and talk to passer-byes about type 1 diabetes. Unfortunately, the activity was less successful than expected, as there were less people in the streets due to it being a national holiday in Iran and Ramadan.

In May 2019, after a flood affected an important area of Iran, Vida and the Gabric diabetes education association reached out to people living with diabetes in the affected areas and cities.

Gabric contacted their members in the those areas and enquired about their need for diabetes medication, to ensure everyone has access to them.
WHCA side event on CVD and diabetes

On Wednesday, May 22, the World Heart Federation (WHF) and the International Diabetes Federation hosted a side event (video stream available here) at the 72nd World Health Assembly in Geneva (Switzerland).

Experts and advocates discussed their experiences and perspectives on CVD and diabetes in a program entitled, Joining forces to fight CVD in people with diabetes: pathways to solutions.

The in-depth discussion focused on Sustainable Development Goal (SDG) 3 “Ensure Healthy Lives and Promote Wellbeing for All at All Ages” and the targets 3.4 – 30% decrease of NCD-related premature mortality.

Two members of IDF’s patient networks participated as panellists. Stela Prgometja (BCV member from Serbia) and Lucas Xavier de Oliveira (YLD member from Brazil) discussed the realities of living with type 1 diabetes (both were diagnosed during childhood) and their own understanding of CVD as a risk factor in their lives.

If you are interested in learning more about this event, click here to read Elizabeth Snouffer’s article on Diabetes Voice.

Disclaimer
The views and opinions expressed by the BCV members within this newsletter do not necessarily represent IDF’s views and opinions.