



Blue Circle Voices NEWSLETTER

DECEMBER 2018



**International
Diabetes
Federation**

The global voice of people living with diabetes



NEWS FROM THE BLUE CIRCLE VOICES NETWORK

Consultation on stigma and discrimination

To better understand the stigma and discrimination from which people with diabetes and their carers suffer and the impact these have on their lives, **IDF will soon launch a new consultation.**

BCV members will be able to share their stories and experiences and the results of the survey will be used to improve the International Diabetes Federation's campaigns aimed at reducing stigma and discrimination.

Participate in the **Blue Circle Voices network's consultations**,
make your voice heard,
and contribute to IDF's future advocacy strategy!

Future of the BCV newsletter

From February 2019, the BCV newsletter will evolve into a shorter and more concise version to facilitate access to the most relevant information. It will be dedicated to the IDF's and Blue Circle Voices network's news. This change of focus is aimed at **improving the readers' online experience.**

In parallel **a blog will be launched** which will include coverage of all the BCV members' activities. It will feature interviews, articles, activities, and a calendar with events to come. On this platform, updates will be more frequent and will bring the BCV community closer together.





INFLUENCE OF DIABETES IN YOUR LIFE

INTERVIEW WITH A BCV MEMBER

Jérôme Kazabukeye (Burundi)

What was your first thought when you were diagnosed with diabetes?

I could not believe the diagnosis. The day after, I took the test again in a different facility. I was scared for me, and scared of leaving my daughters on their own. But that was well before learning that it is possible to live with diabetes.

Had you ever heard about diabetes before your diagnosis?

I had, but I thought it only affected rich people. As I am a refugee in Burundi, I did not even think of diabetes; I had other things to deal with. Since I was accompanying my wife to a diabetes screening, I decided to take part in it as well. Little did I know that waking up every night to pee was one of the main symptoms of diabetes, and that I was living with it.

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

After the second screening, I went through a rough month: I was convinced that diabetes was a death sentence. It was only with the help of other people living with diabetes and thanks to their advice that I learnt to accept the condition.

Has diabetes had a positive impact in your life?

Of course it has! I want people living with diabetes to find acceptance; this is the reason why I created two support groups. The first one is called "Refugees Diabetes Club" and it helps refugees to accept diabetes and to exchange tips and experiences. Together, we agree that although medication provided by UNHCR is very helpful, it is not sufficient. This is why we work together at finding other forms of support. "Akâra", the second



support group, was created for carers and families of people living with diabetes. In this group, we carry out activities such as humoristic shows to raise awareness about diabetes and to promote its prevention. We believe that laughing is the perfect way to help and communicate!

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

The crisis in Burundi is very complex and it hits people living with diabetes very hard. The political instability and the critical economic situation make access to treatments and care very uneven and difficult. Without government support, our physical and mental health is at risk. Another problem that people in the country face is the fear of being diagnosed with diabetes, which prevents many of them from taking part in the screening process.

I believe we also need support in developing better life habits: nutritional advice, sports clothing, stress management workshops, etc. It is urgent to help people living with diabetes actually live their life.

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

I want to see an improvement in the lives of refugees living with diabetes; I want to advocate for our cause and to have an actual impact. I believe we, members of the Blue Circle Voices network, can contribute to a real change in diabetes care and treatment.



INTERVIEW WITH A BCV MEMBER

Kawter Eshneen (Libya)

What was your first thought when you were diagnosed with diabetes?

Well, I could only really think that I would have to inject myself with insulin for the rest of my life. To be honest, I did not entirely understand what diabetes was at that time. Even after starting taking two insulin injections a day, I continued living my life as before. It was 14 years ago, and diabetes education was not really an option. I had to find the information myself by doing research and reading. Things have now changed for the best in my country.

Had you ever heard about diabetes before your diagnosis?

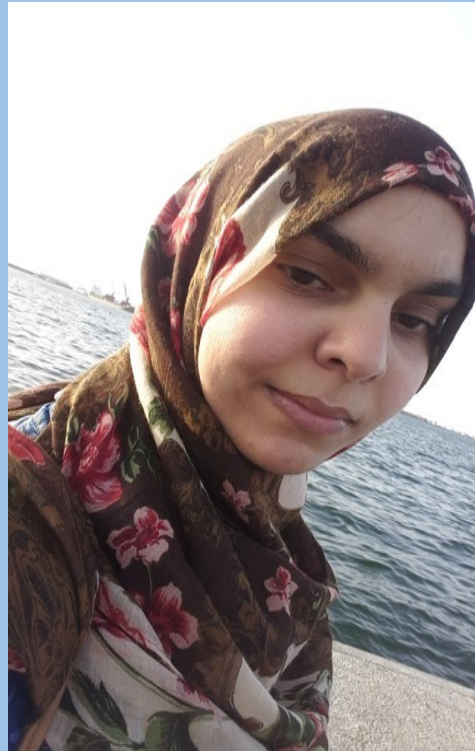
I had, yes. I had this idea that diabetes only affected elderly people. Again, I associated it with lots of injections and syringes. Until I was diagnosed with it, I would never have thought that diabetes could also affect children.

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

After being diagnosed with diabetes, the biggest challenge I faced was learning how to manage my diabetes. I struggled in particular with keeping a normal level of blood sugar. Luckily, I educated myself and learnt about different ways to control my glycaemia. I have now overcome this challenge.

Has diabetes had a positive impact in your life?

Sure! Diabetes changed my life. It was the reason why I decided to join a medical school, so that I could become a doctor. With my background and education, I can now help people newly diagnosed with diabetes understand their condition and provide them with support.



I have been through what they are going through, and I want to ease their experience as much as possible.

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

The biggest challenge in my country is definitely education. As I said before, I did not get a proper chance at being educated about diabetes when I was diagnosed. Things are now changing, but we still have many obstacles to face, and I want to be part of this fight.

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

Living with diabetes is part of my life, and it means a lot to me. I believe in uniting our forces and raising our voices at the global level. Together we can face all challenges, and we can learn from one another. I also hope to trigger changes at the national level, for instance improving access and affordability of diabetes treatments.





A NEW WAY OF THINKING DIABETES

ARTICLE BY A BCV MEMBER



The importance of family support when living with diabetes

By Osarenkhoe E. Chima-Nwogwugu (Nigeria)

It is crucial for people newly diagnosed with diabetes to receive adequate information on the condition, its management and potential complications.

This knowledge is essential to them, and when combined with self-awareness and acceptance of the condition, it allows them to find the strength to ask their family for support.

To me, family support does not only include my immediate family, but also my extended family, friends and colleagues. To find and accept support, people with diabetes must not be in denial: they must have gone through the acceptance process.

Family support can take many forms: eating the same healthy meals, exercising together or getting educated on diabetes and its complications to learn how to act in case of an emergency. Other examples are for family members to accompany the person living with diabetes to their medical appointments and for them to be present in different ways at different times: mental and emotional support when struggling with depression, financial help when needed, and even adapting their language to be more inclusive and respectful of people living with diabetes. In my experience, family support can sometimes prevent complications, and even hospitalisations. This was the case for me when my 15-year-old daughter

provided me with the help and support I needed during a hypoglycaemic event at night.

Having her with me saved my life.

I was diagnosed with gestational diabetes almost 18 years ago. I was lucky to have a lot of support from my husband, my doctors and all my relatives. Thanks to them, bringing my second and third daughters to life was a beautiful experience.

Six months after, I was diagnosed with type 2 diabetes. I discovered what life with diabetes was like in Nigeria. Despite very low awareness of the disease, I made it through thanks to the unconditional support of my loved ones.

The journey of living with diabetes is sometimes so overwhelming that no matter how strong the family support is, it may not seem enough. People living with diabetes may also benefit a lot from support groups where they can share their feelings and experiences and be understood by other people with diabetes. The Diabetes Association of Nigeria, Gbagada, brought me energy and developed in me a sense of belonging I cannot describe. I encourage governments to act towards the promotion of diabetes support groups in order to reduce stigmatisation and tackle misconceptions.

Living with diabetes is a real challenge, but with self-awareness and acceptance, one also finds family support. And family support makes it all easier, trust me.



ARTICLE BY A BCV MEMBER

What happens if you have given yourself the wrong type of insulin?

By Stela Prgomelja (Serbia)

Insulin therapy for people living with type 1 diabetes and some others living with type 2 diabetes includes multi-daily injections. In most cases, people on insulin therapy take two types of insulin: a short-acting one that covers meals, snacks and drinks, and a long-acting one that covers the basal needs of our metabolism. Someone with diabetes should not let out of his sight these two very similar insulin pens, which can only be distinguished by their colour.

Using your insulin pen or syringe for every meal quickly becomes a habit in your daily schedule. But before going to bed, there is one more thing to do apart from washing your teeth – giving yourself a long-term insulin shot, which will cover hormones and help your body stay energised during the day. Year after year, multi-daily injection therapy (MDI) becomes a routine. And with the fast lives that we lead, when the routine settles, mistakes sometimes occur.

We can classify these mistakes into two most common scenarios, which can lead to some serious consequences if not properly addressed:

1. You have given yourself short-acting insulin before going to bed, and in a dose that matches long-acting insulin

What should you do? First of all, do not panic. Yes, it is going to be a long night, but you should stay calm and act wisely. Knowing the dose you injected, you can determine the time of the insulin peak. The higher the dose, the longer the insulin will be active for. Start taking carbs. Determine how many you can eat according to the dose of insulin injected. Combine fast absorbing carbs, such as juice, with low absorbing ones, such as a banana. Test your blood sugar level every hour. Also, do not forget that your body will still need long-acting insulin afterwards: please consult your doctor about the adequate dosage.



2. You have given yourself long-acting insulin before a meal or a snack instead of short-acting insulin

What should you do? Again, do not panic. Your blood sugar may rise, but slowly. Determine the time during which the insulin will be active. Again, keep on testing your blood sugar level. If needed, add a small amount of short-acting insulin. You may enjoy some low carbs, but your meal should be high in protein and vegetables (for instance meat and salad).

Please bear in mind that I am not a doctor. I have been living with type 1 diabetes for more than forty years and my article and my advice are based on my personal experience. For more information on insulin administration or if you have given yourself the wrong insulin and/or dose, please consult your doctor. To learn more about pharmacodynamics and pharmacokinetics of the insulin you are taking, the best source is an endocrinologist.





NEWS FROM THE BLUE CIRCLE VOICES

MEMBERS

ADVOCACY

Betsy Rodriguez (USA)

Community Health Workers (CHWs) play a key role in preventing and managing type 2 diabetes.

Statistics from the US Centers for Disease Control and Prevention suggest that the rate of incidence and prevalence for diabetes in the USA is higher among ethnic minorities. One factor behind this is the uneven access to healthcare in the country.

This is where **CHWs' work is important**: they **promote self-management education** and contribute to **improving the lives of people living with diabetes**, and those at risk.

After conducting a seminar with CHWs and other key stakeholders in May 2018 to discuss the challenges of building an infrastructure to sustain and finance CHWs, Betsy Rodriguez, a Senior Public Health Advisor in the Division of Diabetes Translation at the [Centers for Disease Control and Prevention](#), led a similar seminar on October 5 at the [Vision and Compromise conference](#), a CHW-driven event conducted in Ontario, California, alongside her co-worker, Magon Saunders.

The seminar's title was "Nothing About Us, Without Us: Engaging CHWs/Promoters in Insightful Conversations on Sustainability and Financing".

During her speech, Betsy explained that community health workers' services tend to be funded for limited periods only and that there is a lack of permanent CHW positions in many organisations and health centres. She outlined **ways in which CHWs can be made permanent and sustainable members** of the workforce.

The seminar also highlighted the findings of the May CDC CHW Forum and engaged CHWs in conversations

about their current work conditions and their personal experience of CHW financing and sustainability. It provided an opportunity for participants to listen to other CHWs' perspectives and health promoters about the current policy landscape in this field.

To learn more about CHWs, you can visit the [CDC page dedicated to the topic](#).





NEWS FROM THE BLUE CIRCLE VOICES

MEMBERS

AWARENESS-RAISING

Roxana Vizcaíno (Ecuador)

On the occasion of a collaboration between [Fuvida](#), one of IDF's Members in Ecuador, and the [Metrovía Foundation](#), Guayaquil's integrated urban transportation system, Roxana had the chance to share her experience as a carer of a person living with diabetes.

A meeting on October 1 discussed ways of reducing the moral, social and economic prejudice caused by diabetes to people living with it in Ecuador.

Outcomes of the meeting included organising [blood glucose testing](#) in some stations of the Metrovía transport grid and organising similar glucose testing activities combined with [talks about diabetes prevention and management](#) targeted at bus and taxi drivers. Because of the sedentary habits inherent in their job, **public transportation drivers are at higher risk of developing type 2 diabetes**. This is one of the main reasons which led to the partnership between Fuvida and Metrovía.

There were [talks about diabetes](#) in the morning and the afternoon between October 15 and 18. A total of 300 people attended these talks, during which Roxana gave advice on diabetes management, not only to people with diabetes, but also to their families and carers. It was the **first time that such a large diabetes awareness campaign had been held** in the city of Guayaquil.

The collaboration between Fuvida and Metrovía also included the promotion of [World Diabetes Day](#) through the broadcasting of diabetes awareness videos in transport stations. These invited people to get tested and provided emergency contact details. As the collaboration was very successful, both organisations may continue working together. One opportunity would be to organise blood glucose testing sessions for Metrovía's employees before they start their workday. Using data collected in October and in the future, statistics will be collated to analyse the results of blood glucose testings.



Osarenkhoe E. Chima-Nwogwugwu (Nigeria)

The Gbagada chapter of the [Diabetes Association of Nigeria \(DAN\)](#) organised, on October 11, a meeting in the Gbagada area of the Lagos state, Nigeria.

The meeting aimed at **empowering people living with diabetes, their families and their carers through education and support**. For example, in one of the sessions, the triangle of diabetes management – a schematic way of visualising diabetes care and its core foundations: healthy diet, medication and physical exercise – was explained to the participants. When combined, the three pillars allow for optimal blood sugar monitoring.

The meeting also included talks about the prevention of type 2 diabetes, offering support to people experiencing life-threatening complications and building partnerships with podiatrists to help prevent diabetes complications. The audience was diverse, including people with diabetes, their relatives, healthcare professionals and other stakeholders. In total, around 35 people attended the event. One of the meeting's objectives was also

to help all participants understand the necessity of working together to achieve real success and change.

Not only did Osarenkhoe help with the organisation of the event, but she was also in charge of the membership drive; she presented the sessions, introduced the different speakers, and moderated the talks to ensure the smooth running of the session and equal speaking times between participants. When she introduced herself, Osarenkhoe had the opportunity to mention and promote the Blue Circle Voices network and its global diabetes advocacy mission.

Following the event, new people joined the association. Such meetings, which are held every second Thursday of the month, have a **positive impact on diabetes advocacy** as they help raise awareness and understanding of diabetes in Nigeria. They also contribute to fostering mutual support, encouraging teamwork, and creating a feeling of belonging in the diabetes community.

Narsimha Raju Dichpally (India)

In October, Narsimha continued with the activities that he and the [Lions Club International \(LCI\) District 320D](#) had started in July, which aim at **raising awareness of diabetes, identifying undiagnosed people living with diabetes and preventing type 2 diabetes**.

On October 2, Narsimha helped organise and conduct diabetes awareness and detection camps in Hyderabad. The event was attended by 700 people, mostly from local communities. Doctors presented educational seminars, which focused on diabetes symptoms and diabetes management. Narsimha himself participated as a speaker, talking about the importance of adopting healthy habits to tackle type 2 diabetes and giving tips for a healthy routine.

Since the beginning of the programme in July, 139 camps were held in Hyderabad, Kamareddy, Nizamabad, Armoor, Bodhan, Banswada and Telangana. They reached a total of more than 22,500 people. Of those, **some 20% of the screened**



population was diagnosed with type 2 diabetes. These numbers are evidence of the success of this series of events.

However, LCI's action is not limited to the diagnosis of people with diabetes. It aims to go beyond this and to accompany people with diabetes after their diagnosis. This support includes diabetes education, the prevention of complications, and, with the help of endocrinologists, the provision of medical supplies and treatments such as glucometers and diabetes strips.

At the Lions Club, Narsimha's role also consists in incentivising other members to conduct their own camps and thus contribute to improving the lives of people living with diabetes.





NEWS FROM THE BLUE CIRCLE VOICES

MEMBERS

EDUCATION

Riva Greenberg (USA)

On October 31, Riva was invited to Copenhagen to share her experience of implementing a different approach for health practitioners to work with people living with diabetes. Riva calls it the “Flourishing Approach”. This **aims to change the quality of the relationship and interaction between the practitioner and the person living with diabetes** to ensure the person living with a disease is able not just to cope with their disease, but also to flourish.

In the morning, she presented the concept to health psychology students at the [University of Copenhagen](#). The students were very curious, receptive, and understood the value of approaching people with diabetes as people, rather than as “patients”. In the afternoon, she gave a keynote presentation and facilitated a workshop on some of the “Flourishing Approach” tools to diabetes educators, occupational therapists and researchers

from the [Steno Diabetes Centre](#), a leading research clinic in Copenhagen with five regional sites across Denmark.

Her day ended with a talk with Steno’s CEO, [Allan Flyvbjerg](#), who saw the approach as innovative and welcomed the fact that it is focused on care. Riva described her stay in Denmark’s capital as a wonderful experience and was very grateful to have been able to share a different way of working with people who have diabetes to **help make diabetes care more efficient**, for both healthcare professionals and people living with the condition.

You can read the [article that Riva wrote](#) in collaboration with Boudewijn Bertsch on the topic: “The Flourishing Treatment Approach: A Strengths-based Model Informed by how people create health”, published in December 2016, and [her blog post about her experience in Denmark](#), published on November 5, 2018.





NEWS FROM THE BLUE CIRCLE VOICES

MEMBERS

OTHER ACTIVITIES

Jerry Gore (France) — Fundraising

Jerry Gore is the co-founder of [Action4Diabetics](#) (A4D), a type 1 diabetes charity whose aim is to provide essential care and support to young people living with the condition in South-East Asia.

Despite suffering a serious bike accident on August 10, 2017, breaking his neck and causing extensive nerve damage in his right arm and shoulder, Jerry took part in [A4D's Sea2Summit challenge](#).

Sea2Summit challenge aims at **raising money to support young people living with diabetes in the South-East Asia region**. It is a 220 km bike ride, followed by a 4000m climb to connect the French city of Nice, on the coast, to the summit "Barre des écrivains", the highest mountain summit to be wholly inside France. This explains the name of the challenge: going from sea to summit, in 24 hours.

Following his accident, Jerry went through six months of rehabilitation and six more months of intensive physical training. It was almost one year after the accident that he embarked on the Sea2Summit adventure: on August 26, 2018. The cycling and climbing team was composed of Jerry and four other participants.

You can watch the video of their journey along with some pictures [here](#). The trip lasted a bit less than the 24-hour goal, with a total of 21 hours and 56

minutes. Unfortunately, and due to very critical meteorological conditions (snow, temperatures of 20 degrees below zero, strong winds), the team did not reach the summit.

By facing this challenge and raising money for diabetes in SEA, Jerry sends another message: **diabetes should not prevent people living with the condition from doing demanding physical exercise**, and more generally, from doing anything they set their mind to. He wishes to inspire people to engage in similar projects, of course always with adequate preparation and by putting one's health first.

Jerry and his team raised [a total of €12,500](#). They hope to reach their goal of €40,000 through the presentations they are carrying out in SEA and in the UK. Some €430 per child per year are needed to support the children in need with insulin and test strips as well as provide educational camps, personal development courses and scholarship programs. Jerry's goal is to help at least one hundred children across the following countries: Cambodia, Laos, Vietnam, Myanmar and Malaysia.

You can read more about Jerry's adventure and message on the [article dedicated to his challenge](#) on Action4Diabetic's website.





NEWS FROM IDF

IDF's Response to the UN HLM on NCDs

The United Nations High Level Meeting (HLM) on NCDs, the most important diabetes and NCD-related meeting since 2014, took place in New York on September 27. With the help of many BCV members, IDF ran an intensive advocacy campaign to demand greater action for people with diabetes.

Following its [first statement](#) on the [Political Declaration](#) agreed by the Member States, IDF **will soon release a full response**. This incorporates the results of a consultation undertaken across both the BCV and the YLD networks about their views of the political declaration and IDF's response to it. **The statement will form the basis of IDF's future advocacy strategy**, a key focus of which will be access to medicines and care.



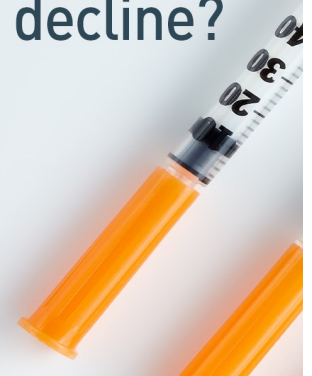
D-NET Discussion

Following [October's talk](#) about sexual health and diabetes and [November's talk](#) on the pros and cons of Metformin being the first-line drug in people with type 2 diabetes, [D-NET's December discussion](#) explores "**Early initiation of insulin in people living with type 2 diabetes**". The debate is led by Dr. Gauranga Chandra Dhar, family physician from Bangladesh.

Registration is free for all. Please do not hesitate to [join the discussion](#) to share your personal experience on the topic, or simply to ask questions.

Your doctor advises you to start insulin treatment.

Would you decline?



D-NET

The International Diabetes Federation **Diabetes Network** for Health Professionals



Diabetes prevention, care and management in humanitarian settings

To raise awareness of the challenges of preventing and managing diabetes in humanitarian settings, **IDF launched earlier in the year a multi-stakeholder initiative** to encourage action, improve health services and ensure access to essential medicines for forcibly-displaced people with diabetes.

This multi-stakeholder campaign involves representatives of the International Committee of the [International Committee of the Red Cross](#) (ICRC), the [United Nations Relief and Works Agency for Palestine Refugees in the Near East](#) (UNRWA), the [World Health Organisation](#) (WHO) and [Santé Diabète](#).

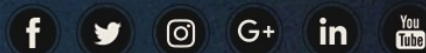
It is supported by a grant from the [World Diabetes Foundation](#) (WDF).

IDF is now calling on all national governments to step up their action on diabetes management, prevention and care in humanitarian settings (by improving access to care and medicines, strengthening health systems and generating data) to achieve the 2030 [Agenda for Sustainable Development](#).

For more information, please visit [our website](#) and watch our [latest testimonials](#) from people with diabetes in humanitarian settings.

66 million people displaced due to conflict worldwide in which **4 million** live with diabetes

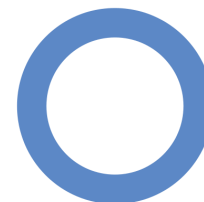
No one left behind



World Diabetes Day 2018

[World Diabetes Day](#) took place on November 14, focusing on the topic “**Diabetes concerns every family**”.

Many of our BCV members have developed WDD activities in their countries during November – **Diabetes Awareness Month**. We will report on some of these activities in the next BCV newsletter.



world diabetes day

14 November

Disclaimer

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

