Diabetes complications campaign

Chris Aldred, a diabetes advocate and BCV member recently diagnosed with a diabetes-related foot ulcer, participated in the IDF Congress in Abu Dhabi last December. There he spoke about the importance of talking with peers about complications. Since then, he has encouraged people to share their stories online through the hashtag #TalkAboutComplications. People from around the world have begun posting stories about how diabetes complications have affected their lives – for many of these people, this was the first time that they have openly spoken about this issue.

Renza Scibilia, a diabetes advocate and BCV member from Australia, who has been writing about how language affects the way we talk about diabetes, believes that we need to reframe the language around diabetes complications to stop the blame and shame that people feel when they are diagnosed with one. In recent months, Chris and Renza have written a number of pieces encouraging people with diabetes to talk openly about their complications and try to feel at ease with it. They are challenging healthcare professionals to reconsider the words they use and to think about the manner in which they communicate with someone diagnosed with a complication.

Building on this inspiring initiative, IDF will soon launch a communication campaign, designed to further raise awareness of complications among people living with diabetes, combat stigma and engage with healthcare professionals around the best ways of tackling complications. Featuring personal stories of people living with diabetes alongside news and education material, the campaign will run on Facebook and LinkedIn and will aim to foster discussion around various complications topics. We would welcome any personal testimonies or other input you would like to provide for this campaign – be it in the form of written or video testimonies or any other material. If you wish to send us material or have any questions, please contact bluecirclevoices@idf.org.
BCV Membership

The BCV network now comprises 123 members from 57 different countries. We invite you to visit the “Meet the BCV” section in our website, to learn more about them.

We are seeking to recruit new members, especially people living with type 2 diabetes or less common types of diabetes (who are currently underrepresented in the network), and people from countries where there is no BCV representation yet. If you know of someone who has diabetes and/or is a carer of a person with diabetes, and would be interested in joining the BCV network, please let us know at bluecirclevoices@idf.org.

Consultations

In February 2018 IDF organised a consultation aiming to understand BCV members’ views of the network.

We are currently analysing the responses to this survey and will shortly share the results on the BCV webpage.

In late April 2018 we launched a new consultation on nutrition education. This consultation has two versions: a basic one, which will allow us to learn more about the type and quality of education received by the BCV members; and a more in-depth version, which will help IDF build a case study on this topic to be presented at an IDF event during the World Health Assembly that will take place on May 22 in Geneva (read more here).

Webinars

From April 2018, IDF will be holding several educational webinars open to its broad network, including the BCV members. Instructions on how to join the webinars have already been sent to BCV Members. If you are not part of the BCV network but would like to join the webinars, please contact bluecirclevoices@idf.org.

In April we organised two webinars for the BCV network: “Diabetes and Social Media” on April 16 (watch again and access the slides) and “Becoming a diabetes advocate around the UN High Level Meeting on NCDs on April 30 (watch again and access the slides).

The next two webinars will be:

- Diabetes and Ramadan: 8 May, 14:00-15:00 CEST
- Advocacy: Messaging and Tactics: 11 May, 14:00-15:00 CEST

We invite those BCV members who have not yet submitted a testimonial, or want to submit a new one, to contact us at bluecirclevoices@idf.org so we can provide them with instructions and advice on how to prepare their videos.

Video Testimonies

Video testimonials are a great way of increasing the visibility of the BCV network and of allowing the voices of the BCV members to be heard.
Bernard Enyia (Nigeria)

On January 26, the Rainbow Hospital Lagos organised a stakeholders’ meeting to discuss diabetes foot care guidelines. This was a follow-up to a five-day training workshop organised by Rainbow Specialist Hospital Lagos in 2017, during which participants committed to the development of diabetes foot care management and referral guidelines for Nigeria. The country currently does not have a national diabetes foot care policy and the document is intended to bridge the gap until such time as a national policy is in place. Bernard Enya was given the opportunity to present existing gaps in the management of diabetes in the country. He also talked about the poor coverage offered by the National Health Insurance Scheme (which does not cover diabetes treatment and drugs), introduced the BCV network, and made some recommendations on creating the guidelines.

Rakiya Kilgori (Nigeria)

On February 10, Rakiya Kilgori, outreach coordinator for the Diabetes Association of Nigeria Sokoto Chapter, attended a State Assembly debate with the Commissioner of Health, members of the State Assembly and non-governmental organisations. The objective of this meeting was to call on the Assembly to pass a bill to ensure that underserved people with diabetes in the country get registered in the National Health Insurance Scheme (NHIS), and obtain higher reimbursement levels for their diabetes medication. Currently, many people in Nigeria cannot afford diabetes medication, as it is very expensive and the NHIS only covers 5% of the cost.

The meeting was a success, and Rakiya’s association is now planning to meet with its members to explain to them how to register in the contributory scheme.
**AWARENESS-RAISING**

**Roxana Vizcaíno (Ecuador)**

On March 5, Miss Ecuador 2017, Daniela Cepeda, dedicated a whole day to the diabetes cause by participating in a photo session with some children of the Puvida Fundación in Guayaquil. Daniela shared a pleasant moment with the children, who explained to her how to self-manage diabetes daily, the way to measure blood glucose levels, how to inject insulin and the difference between having high and low glucose levels. The activity was an amazing opportunity both for the children, who appreciated the recognition of being heard by someone without diabetes, and also for Daniela, who has learned so much about diabetes!

**Delphine Arduini (France)**

In 2017, Delphine decided to tell her story in a comic book for other people with diabetes to see that they are not alone, and for people without diabetes to better understand the disease. “Vivre avec un Diabète/My life with him” was launched on World Diabetes Day 2017 in Paris, and is now available in French and English on this webpage. Similar comic books based on the lives of other people living with type 1 diabetes in other countries/cultures will be launched in the future.

**Osarenkhoe Ethel Chima Nwongwugwu (Nigéria)**

Every second Thursday in Gbagada General Hospital in Lagos, the Diabetes Association of Nigeria (DAN) brings together people living with diabetes, their relatives and friends and a broad range of healthcare professionals (endocrinologists, dentists, nurses, pharmacists, dieticians, physiotherapists etc.) to share experiences and improve people’s knowledge of diabetes. These meetings aim to educate and empower people to help them better manage their diabetes and ultimately, prevent complications (notably amputations) and diabetes-related deaths. The Gbagada DAN meeting is one of six meetings being held at six different hospitals across Lagos. Osarenkhoe Ethel Chima-Nwongwugwu helps organise these meetings, where she assists health care providers with foot screening, glucose testing, blood pressure checking and gives health-focused talks. Not only do these meetings raise awareness of diabetes but also they also help attendees accept their condition and have hope for a better life.
Sheila Vasconcellos (Brazil)

On March 3, Sheila Vasconcellos, Vice-president of the Association of Diabetics of Lagoa, participated in a national TV broadcast, with the aim of raising awareness of the shortage of insulin analogues for people with diabetes in Rio de Janeiro. Despite the fact that these should now be provided as part of the national health system, the economic crisis has meant that only some patients are in a position to access them. At the broadcast, Sheila spoke about the difference between the insulins provided by the Government (NPH and Regular) and the insulin analogues and called on people with diabetes to speak out about the impact that this shortage of medicines, and resulting higher prices, have had on their personal finances.

Sheila has been very active over the last months, attending the 2017 Bakken Invitation Award in Hawaii and the first LATAM Diabetes & Haemophilia Patient Association Leadership Training and Gathering in Panama last January. The Bakken Award is a global programme that recognises and connects people who are contributing to communities around the world through charitable work and volunteerism. The leadership training and gathering brought together existing and upcoming leaders and patient advocates from Latin America in the fields of diabetes and haemophilia for two full days of trainings and experience sharing. Two other BCV members also took part in this event: Vanessa Pirolo (Brazil) and Marcelo Gonzalez (Chile).
Education and Prevention

Adelina García (Guatemala)

On November 24-26 2017, the association EDUMED organised a diabetes camp for children and teenagers (between 7-18 years old) in Izabal (Guatemala). The objectives of the camp, called Endopedia, were to educate young people with type 1 diabetes on carbohydrate counting and insulin sensitivity factor, and to help them realise that nothing is impossible when living with diabetes (from playing and eating your favourite food, to taking care of yourself). Adelina García participated in this camp as a supervisor for a group of children, and taught them self-management, blood glucose measurement, how to inject insulin and carbohydrate counting.

The camp was very successful as it had a real impact in the children participating in it, who learned that they are not alone and that they can reach their dreams if they fight for them.

Basem Futa (Saudi Arabia)

On the occasion of World Cancer Day on February 4, Dr Basem Futa organised the “Diabetic Children Educational and Recreational Event” in Al-Khobar City. The objective was to encourage children with diabetes to adopt a healthy lifestyle, to teach them about self-management and the importance of proper dental care, and to involve parents in the management of their children’s diabetes. During the event, the children composed a song to inspire other children to control their diabetes and lead a normal healthy life. The event was a great success, with 500 people (including children of different ages and their families) attending.

Dr Basem has also been involved in the development of “School Life of a Student with Diabetes”, a guideline providing information for teachers to help them understand type 1 diabetes and the needs of the children who live with it.

Jane Muthoni (Kenya)

Between February 26 and March 2, the Kenya Defeat Diabetes Association (KDDA) organised “Diabetes Peer Educators”, a forum bringing together people living with type 1 and type 2 diabetes for a five-day training on diabetes self-monitoring using the NEST formula (Nutrition, Exercise, Stress Management, Treatment). Jane Muthoni, one of the seminar’s organisers, gave the participants tools to raise awareness of type 2 diabetes in their communities, and to prevent diabetes complications.

One of the seminar’s main successes was an improvement in sugar-management through the four NEST pillars.
Betsy Rodriguez (USA)

The American Diabetes Association held its 65th Advanced Postgraduate Course in San Francisco between February 9 and 11. Betsy Rodriguez, BCV member from the CDC Division of Diabetes and current co-chair of the CHWs Work Group at CDC, participated in the event as a diabetes expert. Her role was to develop and promote two systematic reviews on the contributions made by, and the effectiveness of, community health workers in respect of diabetes prevention and management. She also participated in the panel discussion: Engaging Community Health Workers in Working with Diverse Populations. You can read more about what Betsy learned from this activity on her LinkedIn profile.

Riva Greenberg (USA)

In February, Riva attended a training event, with the aim of becoming certified to deliver the Stanford Diabetes Self-Management Program (DSMP). The DSMP is designed to give basic diabetes education to people living with type 2, many of whom live in communities with few educational resources or who may have low literacy levels.

During the four full-day programme, Riva practiced delivering the DSMP as a Peer Leader. The DSMP classes run one day a week for six weeks and Riva has now been trained on how to provide this education in a way that inspires people with diabetes to feel more confident in their capabilities, take greater ownership for their care and become more skillful in taking care of themselves.

Stela Prgomelja (Serbia)

Stela has launched a Youtube channel and an Instagram profile (diabetes_serbia), to educate people about carbohydrate counting, fats and glycemic index in everyday meals. Since January 14, she has been regularly posting short videos of herself cooking various dishes at home and has so far uploaded 27 recipes – two of which are in English.
WDD 2018-2019 topic

World Diabetes Day is the world’s largest diabetes awareness campaign reaching a global audience of over one billion people in more than 160 countries. The theme for the WDD campaign over 2018-2019 will be “Diabetes and Family”.

IDF is currently working on the key messages and materials for the campaign, which we will share with you very soon.

IDF Diabetes Complications and Foot Congress 2018

IDF has just launched a new series of live educational events to tackle the issues of diabetes complications. The first of these events, the IDF Diabetes Complications and Foot Congress 2018, will be held in Hyderabad (India) between the 24th and 27th October 2018.

We invite you to submit your abstract for this Congress and share your knowledge with primary care physicians, endocrinologists, orthopedists, podiatrists, general and vascular surgeons, cardiologists, nephrologists, ophthalmologists, nurses, educators and physiotherapists from around the world. You can submit your abstract here / the deadline is 31 May 2018.

IDF 2019

In 2019, the IDF Congress will be held in Busan, Korea from December 2-6. With innovative and interactive sessions, the programme will deliver top quality presentations from high-level speakers. Spreading knowledge to healthcare professionals in all fields of diabetes and at all experience levels, the congress will improve healthcare practice and enhance the lives of people with diabetes.

Have your say and help shape the congress programme. We would like to hear what you feel is important in the field of diabetes healthcare today. Please submit your topic suggestion by 14 May 2018 here.
WHA side event

On the occasion of the 71st World Health Assembly, IDF will hold the multi-stakeholder panel discussion, “Nutrition education and IDF action on junk food and serving sizes to tackle obesity and prevent diabetes among children, women and all those at risk” in Geneva on May 22.

During the event, nutrition experts, government representatives and people living with diabetes will discuss how quality nutrition education can be part of the solution to overcome the global health challenges posed by diabetes and obesity. The event will also provide the opportunity to showcase recent developments in the IDF Kids & Diabetes in Schools initiative, a project that aims to foster a safe and supportive environment in schools for children with diabetes, and encourage the adoption of good healthy habits from an early age.

You can find more information about the event and the speakers and panelists on the IDF website.

Diabetes prevention, care and management in humanitarian settings

Worldwide, over 65 million people are displaced as a result of conflicts alone. Many of them are living with diabetes. The International Diabetes Federation (IDF) estimates that 1 in 11 people currently have diabetes. Some studies suggest the rate is higher in displaced populations.

All too often, diabetes care is overlooked in the humanitarian response. Without concerted action at all levels, diabetes will continue to take a heavy toll on displaced populations, overwhelming health systems in countries most affected and hindering global efforts to meet the Sustainable Development Goals.

IDF has launched a multi-stakeholder initiative to make sure the voice of displaced people with diabetes is heard and their needs met. This initiative forms part of IDF’s wider scope of humanitarian actions which include the IDF Life for a Child Programme and Diabetat.

IDF and its partners will build a global advocacy and communication platform to raise awareness of the challenges of preventing and managing diabetes in humanitarian settings, and encourage action, financial commitment and the development of financial mechanisms to improve health services and access to essential medicines and care in the immediate and longer-term response to humanitarian crises.

More information on the initiative can be found here.
UN High-Level Meeting on NCDs

IDF is currently involved in intensive advocacy efforts around the High Level Meeting (HLM) on NCDs that the UN will hold in September 27 in New York, on the occasion of the General Assembly.

IDF’s HLM campaign can only be successful if its networks support our call to action at the national level, by reaching out to national policymakers and media, and making noise on social media. We encourage you to read the toolkit that IDF has prepared on this occasion (available in English, French and Spanish), to learn more about how can you support this HLM campaign in your country.

Stay tuned to our HLM webpage, where we will soon post new materials and resources!

IDF toolkit on CVD

Type 2 diabetes is a major risk factor for CVD alongside other risk factors such as smoking and lipid disorders. In turn, CVD is the most prevalent cause of mortality, morbidity and healthcare costs among people with type 1 diabetes and type 2 diabetes.

To raise awareness of the scope and challenges of CVD in diabetes and promote action at a local, national and global level to tackle the issue, IDF recently launched an Advocacy Toolkit on Cardiovascular Disease (CVD) in Diabetes. The toolkit is designed to outline relevant international IDF, World Health Organisation and World Heart Federation policies and key messages on CVD in diabetes for people living with diabetes and to support the planning and implementation of advocacy initiatives. More information on CVD is also available on the IDF website.