Young Leaders in Diabetes

NEWSLETTER

January 2018
Launch of the IDF Advocacy Toolkit for the High Level Meeting on NCDs

IDF has launched a global call to action on the road to the UN High Level Meeting on NCDs which will likely take place in 2018. For its Members to be able to join this call and develop their own national campaigns, IDF has prepared a toolkit providing a range of information and ready-made templates. [www.idf.org/our-activities/hlm2018](http://www.idf.org/our-activities/hlm2018) IDF will develop a tailored version of this toolkit for use by the YLD members, so they have the opportunity to join the HLM global campaign and to support their diabetes associations in their national campaigns.

IDF Congress 2017

The global diabetes community was united at the IDF 2017 Congress in Abu Dhabi (UAE) between December 4-8, 2017. This Congress gave professionals in the field of diabetes, public health specialists, policymakers and advocates the opportunity to attend scientific sessions on the latest developments in diabetes clinical practice, management, education, prevalence and public health issues.

With over 160 hours of sessions, 330 top-level speakers, 1,000 posters and a record 25 CME credits, the IDF 2017 programme provided delegates with an invaluable learning experience through varied and innovative sessions.

In parallel to the Congress, IDF organised the 4th YLD Training Summit between December 5-8. Some 59 members of the YLD Programme from 51 different countries attended this Summit, which provided them with the opportunity to gain knowledge on advocacy, new technologies, discuss the future of diabetes and learn how to develop regional action plans, as well as attend some of the scientific sessions of the Congress.

The overall feedback from the YLD members following the Training Summit was positive. YLD members enjoyed spending time with other YLD members from various regions and learning about different realities. They found the sessions very interesting, and regretted not having more time to delve further into the topics discussed.

“The training programme is a life-changing experience for young people living with diabetes, it allows you to get an insight of how other people are affected by diabetes from different cultures.

I think that the training was very useful to gather information and lay the foundations for the arduous work that must be done in a team so that the results can be seen over the long term.”
Results of the YLD Committee elections

The elections to the YLD Committee, which is composed of a Representative and a Representative-elect from each of the seven IDF regions, took place on December 8. The role of the YLD Committee is to act as a bridge between the YLD members from each region and the IDF Executive Office, coordinate the internal work of each region and provide regional reports and Action Plans to IDF. Here is the composition of the new YLD Committee:

AFR Region

Regional Representative: Yemurai Machirori from Zimbabwe

Regional Representative-elect: Kagiso Molosiwa from Botswana

EUR Region

Regional Representative: Daniel Végh from Hungary

Regional Representative-elect: Uros Bogdanovic from Serbia

MENA Region

Regional Representative: Lulwa Al-Qaoud from Kuwait

Regional Representative-elect: Aziza Bokhari from Saudi Arabia

NAC Region

Regional Representative: Danielle McVicar from Canada

Regional Representative-elect: Zanique Edwards from St Lucia

SACA Region

Regional Representative: Ronaldo Wieselberg from Brazil

Regional Representative-elect: Lucas Xavier de Oliveira from Brazil

SEA Region

Regional Representative: Apoorva Gomber from India

Regional Representative-elect: Kush Patel from India

WP Region

Regional Representative: Shuk Yi Yu from Hong Kong

Regional Representative-elect: UNDER REVIEW
AWARENESS - Deric Formbuh Nkimbeng from Cameroon

To raise awareness of diabetes on World Diabetes Day, Deric Formbuh took part in a one-day event organised by the local branch of the Cameroon Diabetes Association in Ntingkag Mankon Bamenda during which people were screened for diabetes and hypertension. Out of the 78 persons who were screened on that day, seven were diagnosed with type 2 diabetes, two with type 1 and 15 with hypertension. At this event, Deric also talked about the 2017 WDD theme, “women and diabetes”. He outlined the role of women as carers and managers of the household and highlighted the risks women living with diabetes might face during pregnancy.

Dimitris Kaperdanakis from Greece

Dimitris used his Facebook diabetes blog “sweetstoriesGR: The T1D Forum” to launch an awareness campaign called “A circle for diabetes”. Using the global diabetes symbol, Dimitris adapted the blue circle to create 32 circles representing different aspects of life with diabetes. The project was divided into six themed weeks, covering topics such as diabetes basics, managing diabetes, physical activity and diet, psychology, governmental policies and worldwide statistics. Every week, five new circles were introduced on his blog accompanied by a small text in both Greek and English. People were invited to join the campaign and engage with it by sharing the content and using the official hashtags. During the six weeks this campaign lasted (from October 1 to November 14), it reached a total of 98,800 people.

Matija Ažić from Croatia

Together with his association, Matija asked the town hall to light up the pedestrian bridge of Osijek (Croatia) in blue for World Diabetes Day. Matija and some members of his association gave statements to the media related to WDD, women in diabetes and diabetes in general. Afterwards, the people who gathered at the bridge for World Diabetes Day walked the 3.2 km that separated the pedestrian bridge from the next bridge to promote leading a healthier lifestyle.
Daniel Pylov from Ukraine

On November 12, Daniel, in collaboration with the Ukrainian Diabetes Federation, organised an awareness event in Kiev during which their shared tips about diabetes and how to tackle key issues as well as gave information on new technologies relating to diabetes treatment. This event was not only meant for people living with diabetes, but also for people who were interested in learning more about healthy living and protecting their health. Daniel used this opportunity to share his personal experience of living with diabetes and handling the disease on a daily basis, and discussed the various activities organised at the local level with his Member Association.

Chipimo Chisanga from Zambia

The Diabetes Association of Zambia organised a march around Lusaka on World Diabetes Day. Chipimo led the march from the beginning to the end with another youth member from his association. Together, they also featured on a 40-minutes radio talk show during which they talked about women and diabetes and discussed their own experience of living with diabetes.

Apoorva Gomber from India

Apoorva, along with 17 other coordinators at REVORD – Revitalising our Diabetes, a social support group created to connect the type 1 diabetes community, organised a “Run for a cause” event on November 26, to mark “World Diabetes Awareness Month”. The purpose of this event was to raise diabetes awareness and to destroy the myth that people living with diabetes cannot run a marathon and/or engage in the same activities as others. It was an effective event as close to 100 children and young adults participated in the run. Messages were written on boards along the run contrasting the myths and facts surrounding diabetes. This activity showed that diabetes should not be taboo and that by raising awareness, people can better fight against discrimination and destroy the myths that are often spread about this chronic disease.
**EDUCATION - Shiva Chackan from Trinidad and Tobago**

In July 2017, Shiva participated as a camp doctor and educator in the 13th Annual Camp Cocrico organised for children living with diabetes. Twenty children between eight and 16 years old had the opportunity to attend this four-day camp during which they received education about the various aspects of diabetes management while having fun and playing together. The camp was a great opportunity for both children and their parents to share their experience and realise that they are not alone facing this disease. Holding this annual camp proved very successful. There was a noted reduction in the number of hospital admissions for diabetes-related complications, especially diabetic ketoacidosis, amongst the children attending the camps. This study was conducted over a two-year period, looking at ten children and their hospital admissions before attending the camp and afterwards.

**ADVOCACY - Bruno Carrattini from Uruguay**

Together with his Association and some other scientific societies from Uruguay (Chair of Endocrinology and Metabolism, Society of Diabetology and Nutrition, Society of Endocrinology and Metabolism), Bruno worked on a constitutional petition for the incorporation of insulin pumps into Uruguay’s integrated national health system. This petition was presented to the Ministry of Public Health on November 14. Presenting this petition was the first step to show the government that people with diabetes have a crucial need for insulin pumps. Some patients, due to the characteristics of their diabetes (e.g., people suffering from asymptomatic nocturnal hypoglycaemia or women who wish to schedule their pregnancy) need to be able to obtain certain doses of insulin throughout the day and night, which cannot be provided through conventional methods. Ensuring that every person living with diabetes has access to an insulin pump would allow for better glycaemic control and limit the risk of developing complications.

This petition has received a lot of support from the general public, through social media and the press. Bruno will keep on fighting to ensure that adequate legislation allowing for the provision of insulin pumps into the national health system is put in place.

**Paula Chinchilla from Costa Rica**

Paula has been extremely active over the past couple of months. After participating in the 6th Diabetes Congress organised by the Asociación Día Vida of Costa Rica, where she talked about the prevention of discrimination through education, she was also interviewed on World Diabetes Day on a national TV morning programme called “Buen Día”. This interview gave her the opportunity to discuss life with diabetes as a woman. As this programme is widely watched across the country, it was a great channel to raise awareness.

In September, Paula started a blog, “Live1tblue”, with one of her friends, in which they discuss healthy lifestyle and education about type 1 diabetes. They share information about how diabetes can be managed daily in a positive and efficient manner, giving both a nutritionist’s and a psychologist’s points of view.
Zanique Edwards from Saint Lucia

On April 18, Zanique coordinated a one-day training entitled “Empowerment of Youth Living with Diabetes”, which aimed at empowering newly-diagnosed children by showing them that they are not alone and enabling them to meet other people living with diabetes. During this training, children were taught how to administer insulin injections properly, how to interpret blood glucose readings and how to practice proper foot care. This event was very useful, as many of the participants were not used to checking their blood glucose for example. The event helped them learn, step-by-step, how to do so, giving them more control over their own body.

You can check the entire event by following this link [https://www.htsstlucia.org/landmark-project-targets-youth-diabetes/](https://www.htsstlucia.org/landmark-project-targets-youth-diabetes/)

Estefania Malassisi from Argentina

On World Diabetes Day, Estefania was invited to one of Buenos Aires’ TV channels to discuss the importance of diabetes education. Her appearance was during prime time, which gave her the opportunity to reach a wide audience.

Maria Claudia Berghusen from Peru

On November 11, as a pre-celebration of World Diabetes Day, a discussion was held between doctors and people living with diabetes on different topics related to diabetes to exchange ideas and discuss various issues. Maria Claudia was in charge of giving a talk about the family and work environments, using both her perspective as a person living with diabetes and her professional experience as a psychologist. Having a person living with diabetes as a participant provided a different insight into the issue and gave the opportunity to discuss the different facets of the condition from the perspective of a person living with diabetes.
Weronika Kowalska from Poland

To celebrate World Diabetes Day, Weronika conducted two online actions through her blog’s Facebook page. Her aim was to highlight the meaning of this day for people living with diabetes, showing them that they are not alone with their disease. Her first action was called “Blue Mosaic”. She prepared ready-to-print graphic designs with a text sent by people living with diabetes, which were then used by people to take photographs of themselves while holding this text. She collated the 25 pictures she received, added a blue filter and a blue circle on them to make a blue mosaic. The second action was to ask people living with diabetes or their carers to post their personal stories on diabetes on her Facebook page, so other users could vote for the story they preferred. On World Diabetes Day, Weronika posted the stories that received the more votes on her blog.

OTHER - Tazul Islam Munshi from Bangladesh

Tazul has written a short story that describes the difficulties a person living with diabetes can experience when first being diagnosed.

The Blooming of a Bud

It was a bright sunny day but to me a dark gloomy day. Though the sun was rising to its peak every day but my sun was shrinking gradually to its bottom. I was a young man who can conquer this world in dream but unfortunately I had to count down my last days breathe like an aged old man. The person I became then was essentially opposite to the person I was. A news had shut the door of my all energy, happiness and courage. It seemed as if I was condemned to be doomed.

I had to consider myself as an object with an expiry date in this lively world. Ten thousand commandments were tagged in my brain that thou shall not..., thou shall not..., thou shall not... I am not just blaming my parents for these commandments because mostly these were coming from my neighbours. Their suggestions were making it much harder for me to live. It more likely seemed that I had already lost my right to live in this beautiful world only because I was diagnosed as a diabetic patient. Their suggestions were pathetic for not only me but also my parents. Sometimes I myself felt pity for my poor parents, as I was their only child.

I turned as forbidden man of a forbidden land. It felt like I had done something deadlier than the 7 deadly sins, everything was forbidden for me, even my visit to relatives. I was only permitted to stay in my room like a prisoner in a prison cell. I was only allowed to reveal my diabetes to the doctors. Some people also suggested my parents’ to give me some herbal medicines and homeopaths. It seemed they are wiser than the doctors are. But as a drowning man catches a straw, my poor parents trusted whatever they were suggested and ran from corner to corner to find a permanent cure. My condition did not improve only because of their suggestions other than the specific treatment. In 2013, while I had already spent two years of my university life at the University of Dhaka at last my luck favoured me by bringing me to the door of CDIC (Changing Diabetes IN Children Program) after three years of mistreatment. I was suggested to join an educational group with some other children. As I had already turned an introvert fading youth before its bloom and living in a forbidden land, I sat at the last row behind the children. Just at that moment happened that great flood which brought myself out of the cocoon. A motherly figure with a smiling face told me “Babu, what's your name? Why are you sitting at the back? Please come closer to us” I was astonished! The electric impulse passed through my nerve and for a moment I didn't believe my ear. Then she taught me the things I never heard anywhere since I became diabetic. It seemed she rescued me from the land of death as a saviour of mankind.

From that moment the fading bud became greener day by day. The more I was being acquainted with CDIC the more I was getting the energy to lead a beautiful happy healthy life. When I came to know that thousands of children were enjoying their life with diabetes, I was ashamed at how an enthusiastic energetic young man got himself defeated by diabetes before joining this war. They made diabetes a blessing of God, because it makes us disciplined and teaches us to lead a healthy happy life. Now I am not alone now we are a group of young diabetic persons not patients. We are motivated to bring change and every one of us is working to raise awareness of the people who are responsible for my story. Now we are becoming the powerhouse of CDIC. I feel blessed to be a diabetic person, because it gives me the opportunity to be a Part of CDIC, which is bringing the blooming of the fading buds to its varieties of colours and fragrances.