Young Leaders in Diabetes

NEWSLETTER

December 2018
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.

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.
D-NET’s 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 explored “Early initiation of insulin in people living with type 2 diabetes”. Dr Gauranga Chandra Dhar, family physician from Bangladesh, led the debate.

Registration is free for all. January’s discussion will soon be launched. Please do not hesitate to join the discussion to share your personal experience on the topic, or simply ask questions. Stay tuned to the platform and its monthly diabetes-related discussions.
NEWS FROM THE YLD PROGRAMME

YLD Webinar 2018-2019

All YLD members will soon be invited to the **annual closing webinar of the YLD network** to be held in early 2019. The webinar will first provide participants with an overview of the main activities undertaken by IDF, the YLD network and its members during 2018. The YLD team will also present the changes and projects for the year to come. Finally, live participants will be able to share their thoughts and questions during the **Q&A session**.

Participants will be able to join the webinar live as usual on the following online platform: [https://join.me/InternationalDiabetesFederation](https://join.me/InternationalDiabetesFederation). As always, and for YLD members who cannot attend live, IDF will make the webinar’s recording and slides available online shortly after.

In the meantime, we invite you to discover our previous webinars and to share them with your network.

YLD Committee

YLD candidate from Grenada Lisselle Toussaint resigned from her position earlier in the year. We are delighted to announce that **Diana Estefania Novelo Alzina** from Mexico has been appointed **Regional representative-elect for the NAC region** for the rest of the 2018-2019 term. An up-to-date list of the YLD Committee can be found on [IDF’s website](https://www.idf.org). We wish Diana all the best in her new position!

YLD Individual Project Report Q4

As part of their participation in the programme, all YLD members **develop diabetes-focused individual projects** that respond to the needs of people with diabetes in their communities. They report on them every quarter throughout the duration of the programme. The next report, Q4, is, as every report, compulsory, and is **due by January 6**. During the first weeks of January 2019, and based on the information provided in the reports, the YLD individual projects will be updated and promoted on [IDF’s website](https://www.idf.org).
YLD 2017 Interviews and Training Summit videos

The fourth YLD Leadership Training Summit took place in parallel to the IDF Congress, between December 5-8, 2017 in Abu Dhabi, Saudi Arabia. Some 59 members of the YLD Programme from 51 different countries attended this Summit. For those of you who have not had the chance yet, you can access the interviews on IDF’s website and on IDF’s YouTube playlist.

Please also remember to take a look at the YLD Leadership videos from the YLD 2017 Training Summit. They will provide you with lots of very insightful information on various diabetes-related topics.
NEWS FROM THE YLD MEMBERS

ADVOCACY

Lucas Xavier de Oliveira (Brazil)

On October 23, Lucas attended the third meeting of the Intersectoral Forum to Fight NCDs in Brazil at the legislative assembly of São Paulo. The Forum aims at fighting the main cause of early deaths in the country through dialogue and partnership between the public, for-profit and not-for-profit sectors. Lucas is part of the organisers of the Forum and officially represents the YLDs there.

This third meeting was attended by more than 40 representatives from the government and the other sectors. Together, they discussed ways to improve the fight against non-communicable diseases in Brazil.

One of the meetings’ main highlights was the importance of fostering behavioural change in the population to reduce NCD-related mortality rates. Several participants suggested that encouraging people to lead a healthier lifestyle and to adopt healthy habits such as a balanced diet and regular physical activity already has a huge positive impact on fighting NCDs.

Another key point was the building of strong cross-sector partnerships, not only between the public and the private sector, but also involving civil society and non-governmental organisations that are engaged in one or more NCD-related fields. Making sure that all these stakeholders work together with an interdisciplinary approach is essential to achieving change and success in the long term.

MD Tazul Islam (Bangladesh)

On November 14, the Diabetes Association of Bangladesh organised an advocacy meeting with about 40 key diabetes stakeholders in the city of Dhaka. The object of the meeting was the following: “Challenges of childhood diabetes and role of social partners”.

Mohammad Tazul had the opportunity to participate as a speaker alongside government officers. The meeting was organised as part of the Changing Diabetes in Children programme (CDIC), which aims at providing adequate healthcare to children living with diabetes in Bangladesh. The main objective of the meeting was to work towards making diabetes treatment and medicine affordable for all through increased support from the government and other organisations and partners.
Diana Novelo Alzina (Mexico)

On November 20, Diana had the chance to speak at her Diabetes Association's (AMDS) advocacy meeting in the city of Mérida. The title of the meeting was “Collaborative partnership between the AMDS and the SMNE (Mexican Society of Nutrition and Endocrinology) of Yucatán”. Its main aim was to introduce both organisations and to establish a collaboration with the national movement “Por una sola voz en la diabetes tipo 1”, meaning “Uniting our voices for diabetes type 1”. This movement is the result of a collaboration by 25 diabetes associations in Mexico, and shows the hard work that is being done by civil society to improve the lives of thousands of people living with type 1 diabetes in the country. By uniting, they hope to achieve greater goals and more visibility.

AMDS and SMNE decided to combine their efforts to reduce the ever increasing number of people living with type 1 and type 2 diabetes in the state of Yucatán. Creating a collaboration between diabetes associations and endocrinologists helps reach greater numbers of people with diabetes and to provide them with education. Another goal is to create a registry of all people living with diabetes and to use it to demand greater action from governmental bodies to support diabetes care, education, and prevention.

EDUCATION

Diana Novelo Alzina (Mexico)

On November 16, Diana participated as a speaker at the Health Centre CEMANUD’s diabetes conference on the following topic: “The role of the family in the educational process of a patient with type 1 diabetes”. She highlighted how important it was for family members also to attend diabetes education sessions and for them to include their loved one living with diabetes in all family activities and decisions to prevent feelings of isolation and exclusion.

About 150 healthcare students and professionals attended the event and received relevant and useful knowledge on how to conduct diabetes education, and on how to better understand diabetes education from the patient’s side as well.
Apoorva Gomber (India) - Interview on TCS NYC Marathon 2018

Why did you decide to participate in a marathon? What inspired you to do so?

I wanted to act for the type one diabetes global community. It was the first year that the "Beyond Type 1" organisation opened the call for runners internationally. Every year, their team of runners raise funds for people living with diabetes through the marathon. I applied because I had enjoyed following the previous edition. Although I am no athlete, I got selected.

I was inspired not only by Beyond Type 1’s community and team, who changed my perspective of living with a chronic disease, but also by the many other people with diabetes and loved ones who stay positive through every challenge they face.

The marathon was a way to feel alive and to prove to others and myself that diabetes does not limit us. I also ran to advocate for the rights of people living with diabetes and to break diabetes-related myths.

Why did you choose the NYC marathon for this first experience?

It is very exciting to say that I ran 26.2 miles in New York City, isn’t it? It is like a dream. I feel privileged for this opportunity to join the other runners living with type 1 diabetes as part of the "Beyond Type Run Team 2018" and to fundraise to support the organisation’s advocacy, awareness-raising and research activities.

For how long and how did you train for it?

I started running to escape stress and to monitor my blood sugar level. When I heard I was selected for the marathon, I started training seriously. From April 2018, and with the help of Amy Mckinnon, Reeti Sahai and Gavin Griffith, I adapted my diet and my training plan to prepare for the big event and avoid injuries. I started believing in myself and focusing on the reason for the run: fighting for people with diabetes. After 20 weeks of training, I had built my stamina up and ran up to 30 km.

During the training, were there moments when you thought of giving up? How did you overcome them?

Yes! Definitely. I wanted to give up many times, and combining this intense activity with my personal and professional life was not easy. The main challenge was managing my blood sugar level. I kept altering my basal doses on my insulin pump. When my blood sugar dropped and I was alone, I wondered why I had got involved in this project. I could barely stand and walk. In the end, every run taught me something new about diabetes management and its complexity.
How was the marathon experience?

After travelling from India to the US, I was scared, excited, thrilled and tired. All at once. When the day came, excitement took over the rest of the emotions: this was the day I had been waiting for. The streets of the city were filled with people cheering us and kids shaking our hands, it was mind-blowing. Every mile I crossed was emotional; I was running for each person who supported me and for the whole diabetes community.

My blood sugar level dropped twice, making me feel weak. But I came prepared with protein bars, glucose tablets and energy gel: I was not ready to give up. I enjoyed everything: the human connection, the city, the sounds, the feelings. Whenever I felt low, I found a way and a reason to keep going.

What was your first thought when crossing the finish line?

I knew I would cry, and I did. Before I could process anything else, I saw my friend Mary Lucas and we burst into tears together. We could not believe that we had done it! Then, I started realising I had just run 26.2 miles. It was over now! It took some time to process all the information. I don’t know if it was the cold, the excitement or both, but I could not stop shivering on the way back to the hotel.

What does it mean to you, as a person living with diabetes, to have succeeded at running an entire marathon?

That I can overcome my fears. Sure, there are times when diabetes will overpower me, but if I stay calm and strong, I can take back control. It is hard and exhausting to live with diabetes with the constant monitoring and measurements, sometimes I really hate it. But after running the marathon, I felt that for once, I had changed the score on the board: Apoorva – 1 / Diabetes – 0!

Would you like to run another marathon in the future?

Yes! I sure want to, with more training. I never saw myself as a runner, but training for this marathon helped me realise that running is emotionally liberating and allows you to be the best version of yourself. I wish to keep learning from every run I do, and to explore more on this incredible journey.

Dániel Végh (Hungary)

On October 11, Dániel took part in an event organised by the Egy Csepp Figyelem Foundation: oral screening sessions and consultations with the diabetes-dental working group of the Semmelweis University to celebrate World Diabetes Day. It was the first time that such an event was held in Hungary and more than one hundred screening sessions took place, with a total of about 6000 visitors. The event was supported by the Hungarian Diabetes Association and was featured in a local television programme. In parallel to this activity, Dániel participated in a Youth Blogger event where he shared the European project #RoadtoWDD2018 in cooperation with Yourah.

Diana Novelo Alzina (Mexico)

On November 7, Mérida’s Municipal Council, Mérida’s Institute for the Integral Development of the Family (DIF Municipal), Health Centre CEMANUD and the cycling team Ciclo Turixes worked together to ignite the Homeland Monument in blue as a show of solidarity and support for people living with diabetes. As a member of the Diabetes Association of the Southeast of Mexico, Diana supported and attended the event, alongside 400 people.
Diana Novelo Alzina (Mexico)

On November 7, Sanofi Pasteur organised an awareness-raising event in the city of Mérida, Mexico. The topic of the session was the influenza vaccines and the importance of vaccination on people living with diabetes to prevent virus-related complications, hospitalisations and to reduce related mortality rates. Some of the experts that were present explained that people with diabetes have high risks of developing life-threatening complications if they are exposed to this disease.

Diana participated in the event as a speaker and representative of the Diabetes Association of the Southeast of Mexico, encouraging the 70 participants to get vaccinated.

Aziza Bokhari (Saudi Arabia)

On November 16 and 17, the Saudi Diabetes and Endocrine Association in collaboration with the Diabetes Youth Club (DYC) organised an awareness-raising event to celebrate World Diabetes Day in Dhahran. Aziza participated in the event not only as an organiser, but also as a speaker.

It was the first time that DYC, a club for young people living with diabetes in Saudi Arabia, organised a WDD event. It was held at the Prince Saud bin Naif Park in Dhahran and aimed at strengthening the bond between the diabetes community, and at breaking the stereotypes that surround diabetes. To this end were held “Diabetes talks” which provided the audience with testimonials from people living with diabetes explaining their experience and how they had adapted their lives to welcome diabetes and turn it into a strength instead of a weakness. In addition to the talks, there were also booths where people could ask questions and receive specific diabetes education provided by members of the DYC. About a hundred people attended the two-day event.

Diana Novelo Alzina (Mexico)

On World Diabetes Day, the State of Yucatán Institute for the Integral Development of the Family (DIF Estatal) organised an event to promote the role of the family in the life of someone with diabetes, raise awareness of diabetes and prevent complications.

Diana was one of the speakers at this event. After introducing herself, Diana talked about her life with diabetes and presented her work as a health professional. She explained how her family supported her with her condition, and how she also brings support to her patients. A total of 60 employees from the Institute attended the event.
OTHER ACTIVITIES
EASD 2018 Meeting

Between October 1st and 5th, the 54th Annual Meeting of the European Association for the Study of Diabetes (EASD) was held in Berlin, Germany. EASD is a non-profit medical scientific association which aims to encourage and support diabetes-related research, its rapid dissemination and its application. It is one of the largest networks for diabetologists worldwide and holds an Annual Meeting in a different European city each year with a very broad scientific programme. YLD members Dániel Végh, Uros Bogdanovic and Weronika Kowalska attended the event. YLD member Ahmed A. Sassi from Libya was unfortunately unable to attend live, but, as a member of EASD, he watched the conferences and attended a webinar online.

Uros Bogdanovic (Serbia)

Uros already had the opportunity to attend EASD 2017 Annual Meeting in Lisbon, Portugal. It was for him a great place to meet different people from the diabetes community and to hear about the latest diabetes-related research and news. During EASD 2018 Annual Meeting, Uros attended several scientific sessions, meetings, informal gatherings and visited the industry exhibition area. He was one of the speakers at the IDF Europe Symposium, where he discussed patient-centric care from the perspective of people living with diabetes and patients’ organisations during the panel “Getting all involved on board”. He was present most of the time at the Diabetes Association of Serbia’s booth, where he was able to tell people about the work done in his association and about his participation as a YLD member and as a YLD EUR regional representative-elect position. Uros also took part in the 5K@EASD Run at the Olympiastation of Berlin.

He is very grateful to have been able to attend and participate actively in many of the activities of the largest European diabetes-related meeting, to have met many people and to have learnt a lot.

Weronika Kowalska (Poland)

Weronika viewed attending EASD 2018 Annual Meeting as a great opportunity for herself and for all diabetes advocates to develop knowledge, connect with professionals and find inspirations for new projects. Having the ticket to the event was a dream come true for Weronika and she is very grateful for IDF to have made this possible.

During her stay, she had interesting conversations with professionals from different fields of expertise. In particular, she met with Adrian Sanders, who commended Weronika’s engagement in patient advocacy (as part of the Young Leaders in Diabetes programme and the European Health Parliament movement). Weronika also attended five sessions, one of the most interesting to her being a debate about improving glucose control in type 1 diabetes, where she learnt more about the use of technology in diabetes care. Weronika also participated as a speaker during the #docday_event, where she presented her campaign Connect1on for WDD, a campaign which features online influencers with type 1 diabetes.

The experience was very positive for Weronika who got the chance to continue her diabetes education, expand her professional network and meet with fellow diabetes advocates and bloggers from all around the world.
Dániel Végh (Hungary)

As a PhD candidate at the Semmelweis University in Budapest, Dániel leads a diabetes-related project, which focuses on oral health complications. For this work, he was awarded the Youth Travel Grant of the Hungarian Diabetes Association, which covered his trip to Germany and offered him the chance to attend the EASD 2018 Annual Meeting. Dániel was particularly interested in the latest diabetes care news and technologies and in the #docday event, organised for young people living with diabetes who are dedicated to advocating for the diabetes community. It was the opportunity to meet his fellow YLDs.

Dániel attended several meetings and presentations, had a lot of conversations and tried interesting new diabetes-related devices. He shared his experience via social media with his community, so that his followers could also attend the event virtually. He particularly enjoyed the session by Hacking Health as he has great interest in the newest technological innovations in healthcare. He also participated in the 5K@EASD Run, which he remembers as a great experience, and attended some of the talks held by fellow YLD members, which he found very interesting.

Daniel is aware of the need to work across interdisciplinary teams. Throughout the event, he made contacts with other professionals, not only in the oral health complications field, but also in other fields. In the future, Dániel wishes to attend the event again, maybe as a researcher, a person living with diabetes, an advocate, or all of them at the same time.

eUrMOVE challenge

Physical activity is key to long-term health. For people living with diabetes, it is one of the crucial elements of diabetes care. Regardless of the type of diabetes they have, every person living with diabetes benefits greatly from regular physical activity.

In collaboration with the IDF Europe YOURAH! (Young Advocates Group) and the IDF YLD EUR (Young Leaders in Diabetes European Region), several YLD members participated in the eUrMOVE challenge. Weronika Kowalska, Uros Bogdanovic and Dánial Végh supported it via their Regional Action Plan “Road to WDD 2018” activities. Weronika also contributed to many other aspects including the project’s graphic design, its social media management and the call to participation to many diabetes associations across Europe.

The project consisted in encouraging physical activity to support people living with diabetes by raising awareness of diabetes and of the importance of regular physical exercise. The goal to reach was 365 days (or expressed in hours, 8760 hours). The challenge was open to everyone, living with diabetes or not. All participants were invited to track how long they trained for, and all workout sessions lengths were then added.

The project ended on World Diabetes Day. For its third edition, and thanks to the dedication of many diabetes associations and more than 2000 people who participated in the project, a total of 16,670 hours were collected (more than 23 months, almost the double of the original goal). The most active participants were Macedonia, Serbia, Belarus, Poland, Hungary, Estonia, and Portugal. Many European organisations and diabetes associations were also deeply involved in this year’s Challenge: the Diabetes Association of Serbia and Plavi Krug, the Polish Diabetes Association, the National Diabetes Association in Kosovo, the ProDiab Association of the Republic of Moldova, the Associação de Jovens Diabéticos de Portugal, and the Polish Foundation for Children with Diabetes.

The eUrMOVE challenge 2018 edition was a huge success, not only because of the amazing results, but also because it helped raise awareness of diabetes to a large public and encouraged all participants to stay physically active, even after the challenge was finished.
Weronika Kowalska (Poland)

From October 14, Weronika has been dedicating a lot of her time to her campaign Connect10n. This campaign is her project for the European Patients Forum Programme for Young Patients Advocates. It consists in featuring influencers living with type 1 diabetes on social media to raise awareness of diabetes and strengthen the online diabetes community. The featured influencers are connecting people with diabetes from all over the world by inspiring, motivating and supporting them via social media.

Weronika is presenting the profiles and pictures of the influencers on a dedicated Instagram page and blog. A total of 20 inspiring stories are already available so far, and many more are coming. Some of the featured influencers are members of the YLD programme: Rachel Portelli, Paula Chinchilla Ortega, Stephanie Haack, and Weronika herself.

Chipimo Chisanga (Zambia)

On November 11, the Diabetes Association of Zambia organised diabetes education sessions on the radio and on the television in Lusaka. The aim of these sessions was to raise awareness of diabetes among the general public and improve their knowledge of the disease.

Chipimo participated in the sessions as a speaker: he talked about his experience of living with diabetes, and provided participants with general information about the condition and its management.

Diana Novelo Alzina (Mexico)

On November 10, the Diabetes Association of the Southeast of Mexico, in collaboration with the University Viscaya de las Américas in Mérida organised a series of events to celebrate World Diabetes Day: nutrition games and a rally were some of the activities. The main goal of the event was to highlight the importance of family and team work, to raise awareness of diabetes, and to spend a good time with loved ones.

Diana joined this event as a participant, playing with her and other families. More pictures of the event and of the rally are available on the Diabetes Association’s Facebook page.

Disclaimer

The views and opinions expressed by the YLD members within this newsletter do not necessarily represent the views or opinions of IDF.