



**International  
Diabetes Federation**  
Europe

# IDF Europe Annual Report 2019

## From Tirana to Busan





## Table of Contents

Foreword.....	3
IDF Europe’s Vision and Priorities.....	4
Policy, advocacy and awareness-raising.....	5
Mobilising for Diabetes (M4D) .....	5
Regional Focus.....	5
EU Platform for Action on diet, physical activity and health	
EU Health Policy Platform	
Roundtable discussion “ Diabetes and Chronic Diseases” - The challenge of EU Nutrition legislation	
WHO European Conference on NCDs	
The Lithuanian Diabetes Appeal	
Publications .....	6
Upcoming Papers	
World Diabetes Day.....	6
Collaborations.....	8
With our members .....	8
XVII “Unity for Good” Eastern European Summit	
Eastern European Regional Meeting on Access to Insulin	
Nordic Countries Meeting	
IDF Europe Prizes	
With the wider community .....	8
Embracing Healthy and Sustainable Dietary Switches for you and the Planet’s Health Discussion	
Joint statement with the EU Health Coalition calling on Member States to improve the EU Budget for Health, Innovation and Research	
Joint Paper on Digital Health	
Towards an EU Strategic Framework for the Prevention of Non-communicable Diseases (NCDs)	
Meeting of the Patients and Consumers Working Party (PCWP) at the European Medicines Agency	
EMA Regulatory Science Consultation	
Other Collaborative Activities	
Corporate Partners	
Unifying diabetes care .....	13
IDF Europe Symposium at the European Association for the Study of Diabetes Annual Meeting.....	13
Diabetes Evidence Initiative in Central Europe (DEICE).....	13
EU-funded projects—an update.....	13
Youth.....	15
Youth Leadership Camp (YLC), Şile, Turkey, July 2019 .....	15
European Patients Forum (EPF)’s Youth Group.....	16
Governance and Secretariat .....	17
Regional Council .....	17
Board Meetings .....	17
IDF Europe Board 2019.....	18
IDF Secretariat 2019 .....	19



## Foreword

Dear Friends,

Over the past two years, the Board and Office, supported by our Member Organisations across the Region, further built on the long heritage of the IDF Europe Region to deliver impactful advocacy programmes, strengthen partnerships among key stakeholders and, ultimately, help improve the lives of people living with diabetes. Numerous collaborations led to a series of wonderful initiatives at country, regional and sub-regional levels.

Young people, whom I strongly believe, represent the future of our Members and Region were a key priority of ours over the previous biennium, with the launch of, and support to, the YOURAH network — a group of dedicated young people, who mentor other youth advocates, build capacity in our countries and also develop local, national and pan-regional projects.

In July 2019, the Youth Leadership Camp (YLC), which will celebrate its 10th anniversary in 2020, was held in Turkey. The camp is not only a life-changing experience for all the participants, but it also marks the entry point into the IDF Europe YOURAH network.

Youth has undoubtedly already proven pivotal in raising the voice of people living with diabetes, and will further help us hold governments to account to effect a real, positive change to the lives of people with diabetes and those at risk.

Over 2018-2019, we continued to develop the IMPACT project. As part of this political advocacy work, we celebrated World Diabetes Day on November 14, 2019 with a symposium, held at the European Parliament in Brussels, under the auspices of the Finnish presidency. It is the first time that IDF Europe had gained the support of an EU presidency. This was in no small part due to the tireless work of Marjatta Stenius Kaukonen and the Finnish Diabetes Association.

Earlier in the year, the XVII Summit of Heads of Diabetes Associations in Eastern European Countries was held in Tashkent, Uzbekistan. The summit gathered more than 100 representatives of Member

Organisations and national authorities and was also attended by delegates from the Uzbekistani Parliament and Ministry of Health.

In Lithuania, the Lithuanian Diabetes Association organised, together with the Lithuanian

Parliament, a roundtable discussion on the challenges of diabetes in the country, which was attended by several IDF Europe Board Members as well as representatives of the Lithuanian Ministry of Health, the State Patient Fund and healthcare professionals.

Another significant project in building political advocacy is the Diabetes Evidence Initiative in Central Europe, which aims to share best practices in diabetes policymaking for effective policy and advocacy strategies.

We are also now launching a White Paper tackling the topic of access to diabetes medicines and technologies in our Region, which we anticipate will be a stepping stone for more work in this area in the next biennium.

We had several changes in our Office during the year and I am very happy to announce that Elisabeth Dupont, after a break, is back at IDF Europe in the position of Regional Manager, where she will be able to continue the wonderful work she had previously started, with her usual passion and dedication. I also want to thank Lala Rabemananjara, and all the dedicated staff of IDF Europe who went to pursue other opportunities this year, as well as Sabine Dupont, our consultant, who helped us with all of our activities during the period of change in the Office.

At the end of this term I want to thank, and extend my gratitude to, every Member of the Board as well as each and every Member in our Region for all the efforts and activities undertaken and the achievements made to improve the lives of people with diabetes and those at risk.

**Prof Dr Sehnaz Karadeniz Chair, IDF Europe**





## IDF Europe's Vision and Priorities

In 2019, IDF Europe represented 69 national organisations of people living with diabetes and/or healthcare professionals in 44 countries across Europe.

IDF Europe's vision guided our objectives and activities in 2019, and paved the way for a new strategy in 2020, driven by the recent European elections and constantly-evolving policy framework.

Our work focused on six main areas:

- √ Improving access to care and awareness across Europe
- √ Quality of Life for people with diabetes
- √ Empowering youth
- √ Preventing diabetes and its complications
- √ Partnerships with all stakeholders
- √ Increasing the voice of people with diabetes on all levels (#nothing about us without us)

With a dedicated leadership at the Board and Regional Office level, IDF Europe commits to being an influential and effective diabetes advocate throughout the European Region.

This work is organised around several pillars—policy, advocacy and awareness-raising, communication, partnerships, unifying access to care and youth.



## Policy, Advocacy and Awareness-raising

### Mobilising for Diabetes (M4D)

**Advocacy to improve access to care and medicines and ultimately make a real, positive, impact on the lives of people living with diabetes is central to all IDF Europe activities.** Over the past few years, IDF Europe’s highly successful advocacy strategy has enabled it to become the voice of people with diabetes in Europe and has helped raise the profile of diabetes on the European political agenda.

**In 2019, IDF Europe maintained its focus in this area** through a series of collaborative activities with its member organisations, and as part of its Initiative to Mobilise Parliamentarians to Act to prevent, Care and Treat (**IMPACT**) Programme. Specific initiatives for IDF Europe this year, which will continue next year, include developing stronger relationships with policy-makers at the national level through its member organisations, to bring diabetes on the agenda in the Council of Europe and WHO EURO, and to renew and strengthen its relationships with MEPs, two-thirds of whom are new to the European Parliament (EP), after the recent European Parliamentary Elections. This also includes rekindling the EU Diabetes Working Group at the EP.

### Regional Focus

#### EU Platform for action on diet, physical activity and health

IDF Europe has been a member of this [platform](#) for many years and continues to hold an active role in this initiative, where members share their action plans with each other and log their commitments and objectives.

#### EU Health Policy Platform



The EU Health Policy Platform is an interactive tool to boost discussions about public health concerns, share knowledge and best practices. The Platform invites you to exchange with others, pool your expertise in joint statements and disseminate actions among a wide audience. Register and get involved in European Health Policy!

**ADORA**  
Common online space to boost discussion on health related issues, publish news and events.

**THEMATIC NETWORKS**  
Collaborative networks bringing together stakeholder organisations to produce joint statements on health related developments.

**STAKEHOLDER NETWORKS & COMMISSION AND MEMBER STATE-LED NETWORKS**  
Networks gathering health stakeholders on a specific health policy area and credited upon request by registered users.

**EU HEALTH AWARD 2020**  
For CITIES, NGOs and SCHOOLS/KINDERGARTENS  
Rewarding initiatives aimed at promoting a high standard of public health in Europe.

IDF Europe is registered with this [platform](#), an interactive tool to boost discussions about public health concerns, share knowledge and best practices. The platform fosters exchange with others, helps pool expertise in joint statements and disseminate actions among a wide audience.

#### Roundtable discussion “Diabetes and Chronic Diseases” — The challenge of EU nutrition legislation

On February 5, **IDF Europe, together with MEP Nicola Caputo (Italy)**, organised a roundtable discussion, at the European Parliament in Brussels. The event **aimed to examine the issues surrounding the inclusion or not of Glycemic Index (GI) data under the EU’s nutrition legislation.**

#### WHO European High-Level Conference on NCDs

Held in Ashgabat, Turkmenistan on April 9-10, the conference focused on sharing lessons learned and scaling up action to move forward and achieve Sustainable Development Goal 3.4 over the 11 years that remain to meet the target. IDF Europe was represented by its Chair, Prof. Sehnaz Karadeniz, who spoke at one of the workshops. Prof. Karadeniz emphasised the fact that NCDs are individual chronic diseases with some risk factors in common. But the diagnosis, follow-up and treatments of the diseases are different. Therefore to reduce the burden, there should not be a shift of focus away from individual diseases.

#### The Lithuanian Diabetes Appeal

**In early June, several IDF Europe Board Members attended a roundtable at the Lithuanian Parliament, organised by the Lithuanian Diabetes Association.**



The event concluded with an appeal, of which IDF Europe is a signatory, to Lithuania's Ministry of Health, Parliament, the Presidency and other representatives of decision-making institutions, to:

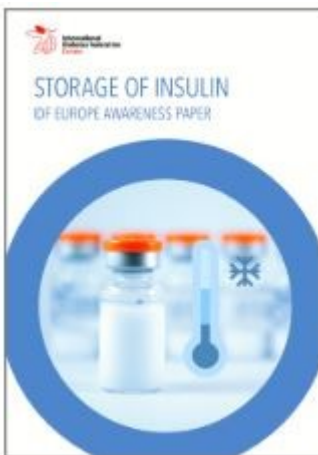
- increase activities to raise awareness of diabetes and its risk factors;
- better organise prevention consultations and campaigns among high-risk groups;
- ensure timely, complete and high-quality diabetes treatment and consistent care and;
- provide accessible care regardless of the region or population group.

## Publications

Publications and white papers are key advocacy tools for IDF Europe, allowing for far-reaching dissemination of its main messages.

### Upcoming Papers

In 2019, IDF Europe started work on three papers:



- **A Paper on Insulin Storage Awareness.** This paper, now published, provides a comprehensive overview of the best ways to store insulin as well as recommendations about best practices in specific situations, such as travelling for example.
- **A Paper on Biosimilars**, based on the *Position on Biosimilars in the Treatment of People with Diabetes*. While the publication has been very well received, publishing a paper in an SCI indexed journal, such as the *Diabetes and Complications Journal*, will ensure broader dissemination and added impact.
- **A White Paper on Access to Medicines and Technologies.** Ensuring that people living with diabetes have access to the right diabetes care, treatment and technologies is paramount to

achieving optimal health outcomes. This is a topic of utmost importance for IDF Europe. This White Paper is based on a workshop conducted with IDF Europe members during EASD in Barcelona in September 2019. It states IDF Europe and its member associations' recommendations on what access to diabetes medicines, technologies and care should look like for people living with diabetes to ensure optimal health outcomes. The White Paper was presented during the IDF Congress in Busan, where IDF Europe and its Members further discussed this crucial topic in preparation of an updated White Paper which will be published in 2020, ahead of a more in-depth publication over 2020-2021.

We thank our Members for their contributions in shaping these papers.

## World Diabetes Day

With our 69 members in 44 countries across the European region, **World Diabetes Day (WDD)** is a major opportunity to build awareness around the management and care of diabetes as well as the prevention of diabetes complications and T2D, with countless activities taking place every year.

For the past two years, IDF Europe has extended its campaign to cover not just WDD itself, but the full month of November for increased awareness of the need for urgent action on diabetes.





At the European level, our direct advocacy efforts are targeted at MEPs and policymakers through events taking place within the European Institutions and we also lead a large-scale awareness campaign aimed at a broader range of stakeholders through a multi-channel communication campaign, which includes media and stakeholder engagements, social media and other communications materials.



In 2019, our campaign included five blood glucose testing events and information sessions at five different European Commission buildings. These were very well received and were attended by XXXX number of people

We also held a lunch symposium at the European Parliament on World Diabetes Day. Organised under the auspices of the Finnish Presidency, the event was introduced by Finnish MEPs, Heidi Hautala and Sirpa Pietikäinen. Focused on improving the well-being of people living with diabetes, the event featured a broad range of speakers from the IDF Europe Board, the European Commission, the Finnish Ministry of Social Affairs and Health and the EUBIROD network amongst others and ended with a call to rekindle the EU Diabetes Working Group at the European Parliament and set up a European Diabetes Registry.

IDF Europe also worked with its collaborating stakeholders to ensure that its message was widely disseminated. One such partner was UEFA, that relayed IDF WDD campaign messages on its social media channels, another, Special Olympics, which IDF Europe helped develop its newly-launched prevention programme.



From left to right—Dr Athanasios Gerakis, European Commission, Marjatta Stenius-Kaukonen, former MP and MEP for Finland, MEPs Heidi Hautala and Sirpa Pietikäinen, Prof Massimo Massi-Benedetti, Prof Dr Sehnaz Karadeniz, IDF Europe Chair



Symposium participants



From left to right: Jaana Lindström, Research Manager, THL, Marjatta Stenius-Kaukonen, former MP and MEP for Finland, Milla Frida Friman, Finnish Diabetes Association, Board Member, Janne Juvakka, Finnish Diabetes Association,



## Collaborations

### With our members

IDF Europe is the voice of 69 national diabetes associations across 44 countries across Europe. Our work to represent their interests and those of the people they serve—influencing policy, increasing public awareness and encouraging health improvement—could not take place without close collaboration and communication—allowing for two-way support as well as information and knowledge exchanges.

---

### XVII “Unity for Good” Eastern European Summit

**Focused on improving collaboration to tackle the rising number of people living with diabetes, the XVII Summit of Heads of Diabetes Associations in Eastern European countries took place in Tashkent, Republic of Uzbekistan, on April 19-21.** This annual gathering aims at improving the cooperation between Eastern European governments to tackle the socio-economic consequences of increased diabetes prevalence and incidence in these countries.

In 2019, the presidents of IDF Europe’s Member Associations from Uzbekistan, Prof Ismailov Said (Endocrinological and Diabetes Association of Uzbekistan) and Dr Ibragimova Nilufar (Charity Public Association of the Disabled and People with DM “UMID”), opened the summit.

Around 100 representatives of member associations and national authorities participated in this high-level meeting, including delegates from the Republic of Uzbekistan’s Parliament and Ministry of Health and regional representatives of the World Health Organisation (WHO), the United Nations (UN) and UNICEF.

IDF President Prof Nam Cho, IDF Europe Chair, Prof Sehnaz Karadeniz, IDF Europe Chair-elect, Dr Niti Pall, and IDF Europe Board Member, Dr Iryna Vlasenko, were also present.

The first day of the meeting focused on the specific challenges faced by the Region as a whole, and Uzbekistan specifically, regarding diabetes incidence, as well as the progress achieved by the country in the prevention, management and care of the disease. Prof Nam Cho also provided a global perspective on the burden of diabetes and IDF’s role in tackling this problem.

During the following day, discussions centred on the best ways of improving cooperation between Eastern European countries to address the high diabetes incidence and its serious socio-economic consequences, specifically towards the implementation and/or improvement of diabetes national plans and the effective cooperation between ministries of health and diabetes associations. To this end, various working sessions were organised, which served to establish better advocacy procedures.

Other subjects of note during the meeting included innovation in diabetes, digital technologies in diabetes management and diabetes with co-morbidities conditions.

The summit concluded with the adoption of the Summit resolution.

Many thanks to Prof Said Ismailov and Dr Nilufar Ibragimova and the entire teams.

---

### Eastern European Regional Meeting on Access to Insulin

Hosted by Health Action International (HAI), with the support from the Health Policy Analysis Center in Kyrgyzstan, this meeting took place in Bishkek, on 14-15 October 2019. It gathered a number of diabetes association representatives—including IDF Europe members—in seven countries (Armenia, Azerbaijan, Belarus, Kyrgyzstan, Moldova, Ukraine and Uzbekistan), alongside representatives from Ministries of Health as well as experts from WHO.





The two-day meeting provided an opportunity to discuss barriers and opportunities regarding insulin access in the region. HAI shared the findings and interventions gathered over the past four years of the ACCISS Study. *More information and tools can be found here:* (<http://accisstoolkit.haiweb.org/>).



Photo: Participants at the Bishkek HAI meeting, 14-15 October

Griffiths. Gavin is the founder of [Diathlete](#). Gavin was diagnosed with T1D at the age of eight, and is now an endurance runner, who has taken over 100 challenges across the world to fundraise and support various causes and charities linked to T1D.

The award is supported by a grant from Lilly Diabetes.

Iryna Vlasenko, IDF Europe Board Member, played an active role in the meeting and underlined the importance of taking into account the civil society voice when making decisions. She also stressed the need for cross-sector collaboration for improved access diabetes care, which is urgently required.

### **Nordic Countries Meeting**

The Nordic Forum, which traditionally gets held annually, did not take place this year and was instead replaced by a series of Skype and phone meetings. The next edition will be in 2020, when it will be organised by the Danish Diabetes Association. IDF Europe looks forward to joining the meeting next year.

### **IDF Europe Prizes in Diabetes**

Each year, IDF Europe recognises excellence, innovation and commitment to diabetes, in the form of an award granted either to an association or an individual.



This year, the Long-Standing Achievement in Diabetes Prize was awarded to an individual, Gavin Charles

## **With the Wider Community**

**IDF Europe strongly believes that preventing T2 diabetes and its complications and improving the quality of life of people living with diabetes can only be achieved through effective, sustainable collaborations** across a broad range of stakeholders — from our member associations to other like-minded associations and alliances, European and international bodies, media, private organisations, networks of people living with diabetes etc.

We disseminate key messages around the burden of diabetes and the need for urgent action and foster discussion around possible actions and solutions through a host of channels and communication tools, such as the IDF Europe [website](#), IDF Europe newsletters and social media platforms. International days are an important communication focus, which help us position diabetes within a broader framework.

Another key mode of action is our participation in various alliances, fora, roundtables and conferences as well as the publication of white papers and engagement in various consultations.

### **Embracing Healthy and Sustainable Dietary Switches for you and the Planet's Health High-Level Discussion (March 7, 2019)**

Co-hosted by the Health Grain Forum and MEP Elena Gentile (Italy), IDF Europe participated in this high-level discussion which set out to study whether whole grains can contribute to improvements in European dietary trends in coming years



## **Joint statement with the EU Health Coalition calling on Member States to improve the EU Budget for health, Innovation and Research**

In early June, IDF Europe alongside 26 other stakeholders part of the EU Health Coalition, released a statement, calling on Member States to adopt a multi-annual financial framework as well as a Horizon Europe budget which echo Europe’s ambition for innovation in research.

## **Joint Paper on Digital Health**

On June 24, 2019, led by Health First Europe (HFE), IDF Europe, alongside 27 other international organisations, released a Joint paper on Digital Health. The paper stated HFE’s digital health vision:

### 1. Priorities for EU action on digital health:

- Citizens’ secure access to, and sharing of, health data across borders;
- Better data for improved research, prevention, and personalized health and care;
- Citizen empowerment.

2. Implementation of existing digital solutions & data sharing practices across Europe (in the areas of prevention, diagnosis, therapy, monitoring and after care)

### 3. Benefits of digital health & health data sharing

- Fostering access to care in remote areas and across borders;
- Improving patients’ empowerment;
- Tackling the growing demand for care;
- Supporting HCPs in their daily work;
- Fostering management of chronic disease and improving patient outcomes.

4. Identifying and addressing the barriers to the uptake of digital solutions



Towards an EU Strategic Framework for the Prevention of Non-communicable Diseases (NCDs)  
Joint Paper



## **Towards an EU Strategic Framework for the Prevention of Non-communicable Diseases (NCDs)**

IDF Europe joined forces with the European Chronic Disease Alliance (ECDA), European Public Health Alliance (EPHA) and Non Communicable Diseases Alliance (NCDA) to call on the European Union Institutions to establish an [EU Strategic Framework](#) for the Prevention of NCDs towards 2030.

The paper sets out basic principles, priorities and actions to tackle the 21st century’s foremost threats to health and well-being.

## **Meetings of the Patients and Consumers Working Party (PCWP) at the European Medicines Agency**

The [PCWP](#) provides a platform fostering discussion and information and knowledge-sharing on issues of common interest relating to medicines, to EMA, patients and consumers. IDF Europe is one of 22 patient and consumer organisations working hand in hand with the European Commission, the Healthcare Professionals Working Party and the EMA scientific Committee and Management Board for the period 2019-2022. It is represented by former IDF Europe Chair (2012-2015), Joao Manuel Valente Nabais, and Board Member, Iryna Vlasenko. On September 24, the PCWP adopted its [work plan](#) for the period 2019-2022.

## **EMA Regulatory Science Consultation**

IDF Europe also contributed to the EMA’s [draft guideline](#), released in June, on the quality requirements for medical devices in human medicines which include a medical device, known as drug-device combinations.



IDF identified the three core recommendations to deliver the most significant change in the regulatory system over the next five years:

- Promote the availability and uptake of biosimilars in healthcare systems
- Contribute to the HTA's preparedness and downstream decision-making for innovative medicines
- Develop the regulatory framework for emerging digital clinical data generation

IDF Europe also outlined the main gaps in the strategy:

- Restoring the trust between Health Technology Assessment companies and the rest of the society
- Taking into account the experiences of health technologies' existing users
- Improving the systems of pharmacovigilance and materiovigilance
- Providing the data needed to adjust the pricing according to the results of real-life studies

## **Other Collaborative Activities**

IDF Europe participated in a number of meetings and other activities during the year. Some of these (not exhaustive) included:

### March

- IDF Europe participated in the "Intrinsic capacities" webinar, which took place on March 5. Co-organised by WHO and [FrailSafe](#), this addressed the challenge of managing declines in intrinsic capacity, with the objective of preventing care dependence in older age.
- On March 27, IDF Europe joined the Patient Workshop on Biosimilars Medicines that took place in Amsterdam. Organised by Medicines for Europe, the event aimed to share the patient's perspective on the potential benefits of biosimilars medicines.
- IDF Europe also participated in the "Joining forces to prevent and control non-communicable diseases: the role of policy in tackling stroke", conference, organised by the Stroke Alliance for

Europe (SAFE), together with the European Stroke Organization and the Romanian National Stroke Association in Brussels on March 28.

### May

- On May 15, IDF Europe participated in the CHRODIS Plus webinar (IDF Europe was involved in CHRODIS' previous edition): Health Promotion and Primary Prevention. The objective was to discuss health promotion and primary prevention of chronic diseases. across the EU.

### June

- Erin Vera, IDF Europe's former Communications Officer, participated in European Public Health Alliance's (EPHA) Annual General Assembly (AGM) on June 26.
- IDF Europe Chair, Prof Sehnaz Karadeniz, shared the patient perspective during Medtech Week (June 3-6).

### October/November

- Elisabeth Dupont, IDF Europe's Regional Manager, joined "Universal Access to Health", an annual policy event organised jointly by the European Patients' Forum, Medicines for Europe, European Social Insurance Platform (ESIP), European Public Health Alliance (EPHA) and The International Association of Mutual Benefit Societies (AIM). This event is designed to promote exchanges between a diverse stakeholder group on how to reach universal access to healthcare.

### November/December

- Elisabeth was also involved in various EU Health Coalition meetings in both November and December in preparation for the new edition of the EU Health Summit (currently postponed because of Covid 19).

Alongside these specific events/activities, we also have general relationships with the above-mentioned and several key European NGOs and other European organisations.



#### WHO EUROPEAN OFFICE

Our collaboration with the WHO European office focuses on joint communication efforts during key important dates such as the World Health Day and World Diabetes Day. We also actively participates in WHO Europe regional meetings.

#### EUROPEAN ASSOCIATION FOR THE STUDY OF OBESITY (EASO)

We work with EASO on a number of prevention initiatives.

#### EUROPEAN CHRONIC DISEASE ALLIANCE (ECDA)

We attend the quarterly steering committee meetings, and coordinate joint calls for more actions in the area of chronic diseases prevention. Also See Joint Paper above.

#### EUROPEAN FEDERATION OF PHARMACEUTICAL INDUSTRY ASSOCIATION (EFPIA)

We work with EFPIA on a number of initiatives, not least the EU Health Coalition, which now gathers a great many EU health organisations in support of calls for an improved healthcare framework.

#### EUROPEAN MEDICINES AGENCY (EMA)

See previous section.

#### EUROPEAN PATIENTS' FORUM (EPF)

As member of EPF, we work on joint initiatives representing the voice of people living with chronic diseases.

#### EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA):

IDF Europe is also a member of EPHA, and we actively participate in the monthly policy coordination meetings.

#### FOUNDATION OF EUROPEAN NURSES FOR DIABETES (FEND)

We closely collaborate with FEND, which annually helps us by supporting our Youth Leadership Camp

#### HEALTH FIRST EUROPE (HFE)

As member, we collaborate with HFE on common advocacy activities at the EU level. Lala, our Regional Officer, is a Board member of the organisation, which holds an annual meeting in Brussels.

## Corporate Partners

We work with a number of private organisations, which through their unrestricted grants, as well as dedicated support to specific projects, help us achieve our goals. In 2019, we started roundtable dialogues with our partners, a concept which has proven very appealing both to IDF and our partners. We look forward to developing this concept further in 2020.

## Unifying Diabetes Care

### **IDF Europe Symposium at the European Association for the Study of Diabetes Annual Meeting**

**From 2011 to 2019: a critical look to the achievement of the NCD agenda for the diabetes community in Europe**

On September 16, IDF Europe held, as in every year, its symposium prior to the opening of EASD's annual meeting. The symposium drew around 60-70 participants who had a very informative discussion on the status of diabetes care in Europe.

Cristina Petrut, IDF Europe Board Member, presented the patient perspective, while Joao Filipe Raposo focused on the adequation between the NCD agenda and the diabetes policy needs. Prof Sehnaz Karadeniz's talk centred on the content and implementation of national plans, while Prof Nebojsa Lalic examined the access and availability of diabetes medicines and technologies before Prof Massimo Massi Benedetti and Prof Fabrizio Carinci looked at the landscape of diabetes registries in Europe.

The main take-away was the remaining disparity of care and access to medicines and technologies, and the need for further concerted action.

### **Diabetes Evidence Initiative in Central Europe (DEICE)**

Together with AstraZeneca, IDF Europe has started a Policy Council across several countries in Central Europe. The Council's main objective is to gather and develop optimal advocacy evidence in several countries

in Central Europe. This evidence will be developed for the topics of most pressing importance across the region, which can then be used broadly by stakeholders in any relevant policy advocacy activity.

The first meeting was organised in Belgrade in February. Following on from this meeting, three expert

groups were put together, by inviting all interested IDF Europe members. These will each release a paper focused on one of the most important themes identified during the meeting — diabetes registries, early access to care and multi-level care. The papers will be published by the time of the IDF Congress in



Photo: Nebojsa Lalic presenting at IDF Europe's EASD Symposium, September 16

Busan.

The second meeting took place in Warsaw on March and the third in September in Prague, during which best practices in diabetes policy-making were shared and approaches by CEE countries discussed, to strengthen efforts to build effective policy and advocacy strategies to reduce diabetes prevalence throughout the Region.

DEICE is a collaboration between IDF Europe and its Member Associations as part of its IMPACT initiative.

### **EU-funded research projects — an update**

Several EU projects came to an end in 2019.

**CarpeDiab – ProEmpower Tender – Integrated e-health solution for Self-Management of Type 2 Diabetes**



CarpeDiab, which aimed to be an advanced service for type 2 diabetes management, concluded in early-2019.

For more information, please visit: <https://proempower-pcp.eu/pcp-contractors/carpediab.html>



The last dissemination meeting for Feel4Diabetes took place in Brussels, in late August. This EU-funded project under Horizon 2020 set out to develop, implement and evaluate an evidence-based and potentially cost-effective, communal and scalable intervention to prevent type 2 diabetes across Europe.

For more information, please visit: <http://feel4diabetes-study.eu/>



September 2019 marked the kick-off meeting of the [Trials@Home](#) project, funded as part of the Innovative Medicines Initiative 2, which will explore the opportunities of moving clinical trials from the traditional clinic setting to the participant's immediate surroundings. Remote Decentralised Clinical Trials (RDCTs) make use of new, digital, innovations and enable participants to visit a clinical trial centre less frequently, if at all.

IDF Europe will be involved primarily in Work Package 5, which focuses on communication, dissemination and stakeholder engagement. More specifically, IDF Europe will help measure and quantify the paradigm change on patients and HCPs between current approach and induced changes in RDCTs as well as develop a checklist on best practices for setting-up a RDCT in the EU .

### Upcoming Projects

New projects are in the pipeline for 2020, not least **Diabetes and Sports**, funded under ERASMUS+.



This project, in collaboration with TSV Bayer 04, HAŠK Mladost, OLYMPIACOS S.F.P., Lazio Volley and Wiener Sport Club, aims to encourage social inclusion and equal opportunities in sport through education on

diabetes and sport, targeted at children, family members, sports educators, teachers and coaches. The project started in late October 2019, with an official kick-off meeting in January 2020 in Brussels.



**RECOGNISED**, Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and

identification of patients at risk of dementia, is a Horizon 2020-funded project, which investigates the common mechanisms involved in the pathogenesis of DR and cognitive impairment in the T2D and use the retina as a tool to identifying individuals with T2D at a higher risk of developing cognitive decline or dementia. IDF Europe is part of the consortium, alongside various academic institutions, EATRIS and Alzheimer Europe.

**ISLET**, Advancing Innovative Stem cell-based Therapy for Diabetes in Europe, is also a Horizon 2020 project, which aims to build and implement a new and innovative programme for the production and marketing of human pluripotent stem cell-derived advanced therapy medicinal products for the treatment of T1D. IDF Europe facilitates the dissemination of the project's progress and outcomes and connection between the various stakeholder groups.



## Youth

IDF Europe strongly believes that youth represents the future of our Region and member organisations. Over 2019, IDF Europe has maintained its youth focus, with the 9th edition of the Youth Leadership Camp, and ongoing support of the YOURAH network, first launched in 2017.

### Youth Leadership Camp (YLC), Şile, Turkey, July 2019

One of the pillars of IDF Europe’s activities, the YLC aims to foster the next generation of diabetes advocates and leaders and provide them with an opportunity to hone their skills, learn about leadership topics, network, and share their knowledge and experience with other youth advocates. The long-term objective is to empower youth to engage in policy and advocacy-related activities by inspiring them through examples of positive leadership, and to build a strong and active pan-European network of young advocates for diabetes.

Over 7-13 July 2019, 22 youth participants from 18 countries met in Şile, Turkey for IDF Europe’s 9<sup>th</sup> Youth Leadership Camp. The camp was hosted by the

Turkish Diabetes Foundation, which we wish to thank for their amazing support.



Photo: Flash Mob in front of Şile’s town hall

Throughout the week, youth participants were coached in a series of topics — policy and advocacy, communication, living with diabetes, leadership, diabetes taboos, trends in diabetes etc. — while also engaging in a number of sporting activities. This is very much central to the camp as physical activity is widely regarded as one of the cornerstones of good diabetes management. As has now become a tradition, a key moment of the week was the [flash mob](#) organised in

front of Şile’s town hall and with the participation of Mr İlhan Ocaklı, Şile’s Mayor.

This year, we are grateful to Ayşe Naz Baykal, a professional video producer and previous YLC participant, for her creation of a video of the camp, which can be seen [here](#).

We would also like to thank Lilly and FEND for their continuing support of the camp.



Photo: YLC 2019 participants, IDF Europe Board Members — Cristina-Maria Petrut (top, 7th from right), Iryna Vlasenko (top, 8th from right) and Kyle Jacques Rose (top, 5th from right), Europe’s Regional Chair, Sehnaz Karadeniz (top, 4th from right), IDF Europe YLC Coordinator, Sabine Dupont (top, 5th from left), Sebnem Guneyman, Diabetes Coach (top, 2nd from right), and camp doctor, Dr Neslihan Aydin (far right), YOURAH members, Anastasia Babileva (top, 3rd from right), Uros Bogdanovic & Jelisaveta Folic (middle, 5th and 6th from left)



In 2020, the YLC will celebrate its 10th anniversary. This will provide IDF Europe with the opportunity to further develop its educational offering—beyond the camp—to ensure a maximum number of youth advocates can be coached to become future leaders in the diabetes community.

## **European Patients Forum (EPF)'s Youth Group**

IDF Europe Young Advocate representative, Louise Piersman, joined the EPF Youth Group and participated for the first time in EPF's Spring meeting on April 10-12 in Antwerp, Belgium. Composed of young people with chronic diseases between 15 and 29 years' old, the role of the EPF youth group is to communicate the needs and expectations of young patients to EPF and its members. Participants in the Spring meeting followed up on ongoing projects and provided an opportunity to discuss topics affecting young people with chronic diseases, such as challenges faced in the work environment and sexual stigma.





## **Governance and Secretariat**

### **Regional Council & TEAM Meeting**

Traditionally, every two years, IDF Europe holds its Regional Council (RC) prior to the IDF Congress. This year, 61 Member Associations participated in the meeting held in Busan on December 1st, 2019.

Activity and financial reports were presented and adopted by the Regional Council.

A new Board was also elected to serve IDF Europe from December 2019 to December 2021. Chair-elect, Niti Pall, became IDF Europe's new Chair. Professor Nebojsa Lalic (Serbia) was elected as chair-elect and Dr José Manuel Boavida (Portugal) and Mr Bastian Hauck (Germany) were re-elected for a second term. We also welcomed five new Board Members, Chris Aldred (United Kingdom), Aldona Danyliene (Lithuania), Stella de Sabata (Switzerland), Konstantinos Makrilakis (Greece), Tatjana Milenkovic (North Macedonia) and Alojz Rudolf (Slovenia).



### **Board Meetings**

The 2019 Board Meetings took place as follows:

Board Meeting 1—Brussels, 16 February

Board Meeting 2—Vilnius, 1 June

Board Meeting 3—Barcelona, 16 September

Board Meeting 4—Busan, 1 December



## **IDF EUROPE BOARD 2019**



**Prof Dr Sehnaz Karadeniz**  
Regional Chair  
Turkey



**Dr Niti Pall**  
Regional Chair-elect  
United Kingdom



**Prof Nebojsa M Lalic**  
Secretary  
Serbia



**Mr Alojz Rudolf**  
Treasurer, co-opted  
Board Member  
Slovenia



**Ms Sandra Bršec Rolih**  
Treasurer (resigned March)  
Croatia



**Mr Kyle J Rose**  
Board Member  
France



**Mr Bastian Hauck**  
Board Member  
Germany



**Ms Vida Augustiniene**  
Board Member  
Lithuania



**Prof José Manuel Boavida**  
Board Member  
Portugal



**Ms Cristina Petrut**  
Board Member  
Romania



**Dr Iryna Vlasenko**  
Board Member  
Ukraine



## **IDF EUROPE OFFICE 2019**

Alphabetical Order



**Elisabeth Dupont**  
Regional Manager



**Sabine Dupont**  
Consultant



**Ignacio Garamendi**  
Regional Manager  
(until May 2019)



**Ernest Kararunga**  
Professional Officer  
(until October 2019)



**Winne Ko**  
Policy Officer  
(until September 2019)



**Erin Vera**  
Communications Officer  
(until July 2019)



**Lala Rabemananjara**  
Regional Officer