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## **ANNUAL REPORT 2007–2008**

### From Dublin to St Julians

#### **Introduction**

Over the last few years, IDF Europe has grown significantly as an organisation. This consistent growth can be seen in the scope and number of activities in which the organisation has engaged; but also in the subsequent growth in its reputation as a key stakeholder and valued partner in diabetes policy issues and in health policy in general. In order to sustain this growth IDF Europe should continue to take advantage of the increasing number of opportunities which are arising, at EU level as well as at the level of the Inter Parliamentary Assembly, the Council of Europe and of the World Health Organisation.

IDF Europe currently has the following main streams of activities

- 1) EU Affairs
- 2) Member Association Development
- 3) Council of Europe
- 4) Creation of a diabetes coalition and building partnerships with other key stakeholders
- 5) Engagement with IDF Global as one of the 7 regions of IDF
- 6) Sub-regional activities
- 7) Other initiatives such as the Diabetes Prevention Forum

While the level of IDF Europe activity has continued to grow, it should also be recognized that the resources, both human and financial, required to support this level of activity have not increased at the same rate. IDF Europe currently relies on a small number of dedicated board members, working voluntarily, to represent the organization in all of its activities and supported by a comparatively small professional office.

Apart from the Board's activities on the level of the European Union, the World Health Organisation, the Council of Europe, the Corporate Partners and the sub-regions of the Federation, the work at national level has more direct impact on the lives of people with diabetes. For that reason the Board would like to thank the ten thousands of volunteers within the member associations for their continuous efforts to improve the lives of people with diabetes. Special thanks to the healthcare professionals who give so much spare time for the sake of diabetes and diabetes associations.

The General Assembly / Together We Are Stronger meeting (GA/TWAS) took place in Dublin from 21 – 23 September 2007. The TWAS meeting was held in plenary sessions, which resulted in a request to continue simultaneous workshops in the future. At the end of the General Assembly President Tony O'Sullivan informed the Assembly that he would step down and that Eberhard Standl, President-Elect would take over his tasks as President until the next elections.

During the General Assembly in 2007 elections took place for two vacancies in the Board and one vacancy in the Nominating Committee. Elected as members of the Board were Ms Sehnaz Karadeniz (Turkey) and Ms Elena Shelestova (Georgia). Ms Zulaykho Shamansurova (Uzbekistan) was elected as a member of the Nominating Committee.



The main tasks of the members of the Board are (summarized):

Eberhard Standl (President)	Spokesman, Corporate Partners, office, member Board of management and Executive Board IDF Global, member association relations
Chris Delicata (Vice President, Treasurer and Secretary)	Deputy-President and finances, member of Executive Board IDF Global
Vida Augustiniene	Children and adolescents; Discrimination
Michael Hall	EU Affairs, National Diabetes Programmes, Public Affairs
Helmut Henrichs	EASD, EURADIA, Editorial Committees Medical Development & Technical meetings
Laszlo Madacsy	Central European Countries, DEPAC Children and Adolescents
Alexander Mayorov	Eastern European Countries
Soteris Yiangou	Central European Countries, DEPAC
Sehnaz Karadeniz	Member Associations Relations
Elena Shelestova	Eastern European Countries and Discrimination

Due to the resignation of Tony O'Sullivan at the end of the Dublin 2007 General Assembly the Board was faced with one vacancy on the Board, and decided to co-opt Joao Nabais from Portugal until the next election in 2008. He took upon himself the task to help Michael Hall with the portfolio EU Affairs. The Board also decided to co-opt Alojz Rudolf from Slovenia, in order to help Chris Delicata with the finances of the Region.

The way of working relies on the following principles:

- shared responsibility
- according to individual or shared and approved portfolio's
- no exclusivity on the individual or shared portfolio's for anyone.

The effectiveness and efficiency has been proven and a continuation of this working method will undoubtedly be the case.

The General Assembly and TWAS meeting in 2008 will be held in St. Julians, Malta (19-21 September) on the invitation of the Maltese Diabetes Association. On behalf of IDF Europe: Congratulations with the organization of these IDF Europe Annual Meetings.

## 1. EU Affairs

In 2007, IDF Europe continued to develop its activities in the area of European Union (EU) affairs, building on the successful work carried out over the past few years. Its significant presence at the European Health Forum in Gastein (where we held two workshops on pressing issues in diabetes), the continued engagement with the European Parliament through the Diabetes Working Group and its successful outreach to the Commission's on the legislative proposal on Food Information to Consumers (Food Labelling) are just a few examples of the work which IDF Europe has carried out over the last 12 months.

IDF Europe's primary EU policy objective remains to drive the development of an EU strategy for diabetes – specifically, an EU Council Recommendation on Diabetes Prevention, Early Diagnosis and Control. In order to make progress in the development of EU health policy on diabetes, the Board recognized that it must continue to engage with the EU's institutions, diabetes and other health-related stakeholder groups, while leveraging existing (and future) opportunities to raise the profile of diabetes at EU level.

The focus of activity over the past 12 months was to maintain pressure on the EU's institutions, particularly the European Commission, and to ensure follow up to the previous calls to action from Members of the European Parliament (MEPs), Ministers of Health, and, more recently, the United Nations (UN).

In 2008, key priority for IDF Europe was the launch and dissemination of the second edition of the diabetes policy audit as well as responding to the Commission's Food Labelling proposal, which is scheduled for adoption under the co-decision procedure by 2009. A new priority was to engage directly with the new EU Commissioner for Health, Androulla Vassiliou, following the departure of Markos Kyprianou in February 2008.

Moving towards 2009, IDF Europe also focussed its attention on the European Parliamentary elections in June 2009 and other institutional changes. This will not only mean many new MEPs, but also a new European Commission and potentially a new Commissioner for Health. We shall have to build new relationships within the EU institutions and in particular to encourage the establishment of a new European Parliamentary Diabetes interest group. This should present opportunities for collaborating with other key diabetes stakeholders in our region.

### Food Labelling Directive (Legislative)

Having succeeded in influencing the Commission's draft proposal for a Directive on Food Labelling (adopted 30 Jan 2008) that carbohydrate information (essential for managing an individual's diabetes) would be displayed on the front of food packaging, IDF Europe must now ensure that this new provision passes safely through the co-decision procedure of the European Parliament and Council and appears in the final legislative text.

IDF Europe is building on the initial work in this area and will implement an EU and national lobbying programme to influence the EU decision-making process with the vital support from its member associations in the 27 EU Member States. Activities will be targeted at the EU's institutions, national governments, food industry and other EU health advocacy groups.

### PARNUTS (Foods for particular nutritional uses) Directive (Legislative)

In preparation for the Commission's expected proposal to review the current legislative provisions for "diabetic foods", IDF Europe has held meetings with the Commission and produced a position paper in order to explain the needs of people living with diabetes. IDF Europe maintained that specific "diabetic foods" are not required in order to manage diabetes. The Commission has indicated that it accepts this position and it is now subject to the co-decision process which IDF Europe will continue to monitor.

### Other Relevant Issues (Non-Legislative)

In order to demonstrate its role as a key stakeholder and valued partner in diabetes-related policies and health policies in general, IDF Europe provided input and advice on relevant EU policy discussions in the area of health. Recent and upcoming opportunities included the Commission's White Paper on Obesity, Patient Safety and the EU's proposed fruit and vegetable scheme.

### Launch of the 2nd Edition of the IDF Europe-FEND EU Diabetes Policy Audit

This autumn marks the launch of the second edition of the IDF Europe and FEND EU Diabetes Policy Audit entitled "The Policy Puzzle: Is Europe Making Progress?" The latest report provides a snapshot of the current actions being taken by EU Member States to tackle the diabetes epidemic and, specifically, looks at progress made since the first edition of the report carried out in 2005. The aim of the report is to highlight the disparate national policies and practices across Europe which are, in effect, contributing to the continued growth of diabetes.

When IDF Europe and FEND undertook this first ever benchmarking of diabetes policy in 2005, the results were discouraging – only 11 out of 25 member states had a national framework or plan for diabetes, and where they existed, these plans and guidelines differed significantly among member states, particularly in their implementation.

Although the findings were alarming, the 2005 report served as an invaluable tool, providing comparative documentary evidence on the diabetes epidemic and measures in place to address this problem. With this evidence, politicians were made to take note and started to call for action. The 2005 audit was the basis for some critical policy developments thereafter:

- In April 2006, the European Parliament adopted a Written Declaration calling for a coherent pan-European strategy to urgently take up the disease as an EU public health priority
- In June 2006, under the auspices of the Austrian Presidency of the EU, the Council of Ministers adopted Conclusions calling on Member States to take action on diabetes

It was also evidence for the Unite for Diabetes Campaign which led to , the United Nations adopting a Resolution on Diabetes (61/225) in December 2006.

However, since 2006, there has been little further action in developing an EU strategy for diabetes, despite the increasing amount of data showing the growing diabetes epidemic. The one area of significant progress has been in diabetes research in Public Health projects supported by the EU (see below).



The 2008 audit, expanded to include Romania and Bulgaria (following their accession to the EU), and three other neighbouring countries, paints a similarly worrying picture of diabetes policy to that presented back in 2005 and underlines the serious shortfalls that continue to exist.

In the European Union, diabetes prevalence estimates now stand at 8.6% of the population aged between 20 and 79 years -- up from 7.6% just three years ago. This means that over 31 million people are now living with diabetes in the EU – equal to the combined populations of Spain, Portugal and Lithuania! Many of the people newly affected by diabetes are from vulnerable groups of society, including children and immigrants

Despite this background, the 2008 report also reveals striking differences in the way that countries prioritize the prevention, treatment and management of this often preventable chronic disease. Still less than half of EU member states – 13 of 27 – have a national diabetes framework or plan in place.

Next year will mark the 20th Anniversary of the signing of the 1989 St Vincent Declaration, when, supported by WHO Europe, almost all of the European governments surveyed in the audit committed themselves to act on a series of recommendations to tackle the growing diabetes epidemic, including the creation and implementation of a national diabetes framework or plan.

While this marked a turning point in Europe's fight against diabetes, progress in achieving these recommendations remains frustratingly slow.

This latest audit represents a vital contribution to our common fight against diabetes by compiling data and national practices in a way that helps to promote best practice and facilitates the task of national and European policy makers to make diabetes an effective national, European and global priority. The audit demonstrates the difficulties which even the best organised health care systems have in establishing basic data, moving into prevention and early diagnosis and managing diabetes and its complications.

IDF Europe and FEND believe that the EU should be offering leadership to assist its member states and remain convinced that part of the solution lies in the adoption an EU Council Recommendation urging member states to follow widely recognized best practice in the prevention, care and management of diabetes.

It is only by acting together can we begin to have an impact on the diabetes pandemic.

#### Ongoing Advocacy/Lobbying Activities

It is intended that following the launch event and dissemination of the audit report, IDF Europe and FEND will continue to use this as a key communication tool with both EU and national policy makers in working towards its ultimate objective of securing an EU Council Recommendation on Diabetes Prevention, Diagnosis and Control.

#### European Parliamentary Diabetes Working Group Meetings (2-3 per year)

Members of the European Parliament have, to date, been crucial in raising awareness on a range of policy issues affecting people living with diabetes while also maintaining political pressure on the European Commission to act. The Written Declaration on Diabetes,

adopted in April 2006, is just one example. This level of support must be sustained and strengthened in the next two years, while taking account of the upcoming European Parliamentary elections in June 2009 which are likely to result in a change in the MEPs currently interested in and active on health issues such as diabetes.

IDF Europe supported the three co-chairs of the Diabetes Working Group - MEPs John Bowis, Dorette Corbey and Georg Andrejevs - in organizing three meetings on a range of subjects including 1) importance of food labelling to diabetes; 2) living with diabetes and the risk of complications; 3) diabetes and children. IDF Europe explored ways in which the MEPs can follow up on the EP Written Declaration of two years ago and increase pressure on the European Commission to initiate policy in response to its recommendations.

#### EU Platform for Diet, Physical Activity & Health

IDF Europe, through its Diabetes Prevention Forum initiative, continued to be a partner on the EU Platform on Diet, Physical Activity and Health, participating in the discussions of the Forum and contributing to parallel initiatives being undertaken by other partners.

#### High Level Pharmaceutical Forum (HLPF) – Information to Patients Working Group

The EU's current discussions on the reform of the Information to Patients regime across Member States provided IDF Europe with another good opportunity to raise the profile of diabetes. The HLPF's Working Group's consideration of a diabetes information model on diabetes, in particular, required the input of IDF Europe and was monitored throughout the process in order to ensure that the voice of both patients and professionals is heard. IDF Europe was also a member of the EMEA/CHMP Working Group with Patient Organizations which has also contributed to these discussions.

#### EMA Working Group with Patient Organizations

IDF Europe's invitation to become a member of the European Agency for the Evaluation of Medical Products (EMA)'s Working Group with Patient Organizations was another opportunity to present the voice of people with diabetes. Supported by the European Commission, this cooperation enabled IDF Europe to encourage decision makers to ensure that new medicines reach people with diabetes as quickly as possible, treating the disease and its complications, but also improving the quality of life of people with diabetes.

#### Other European Conferences/Platforms

IDF Europe continued to monitor and identified other platforms which provided an opportunity to raise the profile of diabetes among EU and national policy makers. The European Health Forum in Bad Gastein in October 2007, for example, was an excellent opportunity to meet with both national and EU policy makers, together with other key diabetes stakeholders in an informal networking environment.





#### Funded Projects: IMAGE, SWEET, DIAdvisor and AP-at-home

IDF Europe's involvement in European Commission funded, diabetes-related projects has continued to grow. The IMAGE project, which was already underway, is one example of the funding received from the EU's Public Health Action Programme, where IDF is currently contributing as a cooperative partner. A second project, SWEET, has also now been accepted by the Commission to look at children and diabetes. IDF-E is also a partner on the DIAdvisor project, which started in March 2008. In February IDF Europe was asked to be a

partner in the AP-at-home project (Artificial Pancreas at home). The submission to the EU was executed on March 6. IDF Europe contributed the time and expertise of its board and staff to these EU-funded diabetes projects and will continue to do so throughout their duration.

## **2. Member Associations Development**

### Association Development Training Courses

Through the organization and implementation of a series of training courses, IDF Europe aims to facilitate the accelerated development of its national member associations across the region, particularly in Central and Eastern Europe.

These workshops will focus on organizational aspects of associations, media skills including the development of association magazines, relations with professionals and corporate sponsors and skills in advocacy and government relations.

The workshop took place on 17 and 18 September in St Julians, Malta.

### Association Development Officer (ADO)

Building on the association development training courses, IDF Europe also aims to improve the interaction with national member associations across the region to accelerate their development. The ADO, Mr Cristian Andricu, visited several Eastern European and Central European countries, forming partnerships between associations in the East and West of the region, advising the IDF Europe board on member association needs, and, where required, performing an ambassadorial role in governmental representations.

### Website

The IDF Europe website is an essential tool which should enable national member associations, as well as other third party stakeholders to access the latest information on IDF Europe's activities. Although maintained by IDF Global, the IDF Europe website will benefit from restructuring and updating. In the period 2006-2007 an intranet was developed and introduced at the TWAS meeting in Dublin. However, due to technical problems the intranet has not been fully functioning, and the Board will try to implement the intranet as soon as possible, in order to facilitate the member associations to make full use of the facilities.



### **3. The Council of Europe**

In February 2006, IDF Europe was recognized by the Council of Europe as an International Non-Governmental Organization (INGO) which enables IDF Europe to attend Council of Europe meetings on matters which relate to health and social issues. Although not one of IDF Europe's main targets for its advocacy activities, it is, nevertheless, one more platform to raise the profile of diabetes and to encourage countries both within and outside the EU to support the development and implementation of national diabetes-specific policy.

Throughout the year IDF Europe was able to attend two meetings of the INGO's on health and social issues.

Following the restructuring of the CoE activities, INGO amended its bylaws in order to streamline its activities and to increase the match between the INGO initiatives and the targeted offices or departments of the CoE. Unfortunately the restructuring process consumes too much time and effort and the effectiveness of the INGO group is still to be demonstrated.

At the same time contacts were made with the Secretariat of the Social, Health and Family Affairs to discuss the procedure and opportunity to trigger a Committee of Ministers' recommendation on diabetes. This is following the interest expressed by several representatives of diabetes organizations from countries that are not members of the EU to have a more concrete document on diabetes supported by a CoE recommendation. The discussions proved that: the present leadership of the CoE is more inclined to support social and health topics, so it is a good time to act, if the IDF Europe board will decide to go for a CoE recommendation; out of the documents that may be issued by the CoE, the best to fit our needs would be a "recommendation" (proposals addressed by the Assembly to the Committee of Ministers, for implementation by that Committee or the governments); considering the experience with the EU declaration and the UN Resolution, the draft might be prepared and submitted before the end of September or before the spring session so that the proposal for a new CoE recommendation on diabetes might be submitted for the vote of the Parliamentary Assembly next year; the new document might be improved in areas that proved to be less effective with other recommendations (EU or UN), or it might offer more direct leads to what should be done in order to decrease the burden of diabetes across Europe. If such an initiative will be taken, the interested associations and other stake holders in the area of diabetes will have to be engaged so that the proposed document will inherit the ownership and expertise of all these groups.

IDF Europe will continue to monitor and contribute to the activity of the INGO and the health grouping.

### **4. Creation of a diabetes coalition and building stronger relationships with other stakeholders**

The European diabetes community has already demonstrated its ability to work together in raising the profile of diabetes. The diabetes session at the 2007 European Health Forum in Gastein, in cooperation with FEND, PCDE, and EURADIA was a clear indication of this willingness to cooperate.





By demonstrating a high level of cooperation between these organizations as well as a clear alignment on calls for action from the EU's institutions, the diabetes community reinforced its messages among policy makers and will be more likely to succeed in driving change. IDF Europe therefore continued to work with its partners. On the occasion of the Celebration of World Diabetes Day 2007 a coalition was formed with EURADIA, FEND and ISPAD and with several of the Corporate partners.

Increasingly, there are also opportunities for closer cooperation with other non-governmental organizations involved in the area of chronic diseases and on health issues more generally. Groups such as the European Heart Network (EHN), the European Society of Cardiology (ESC), Health First Europe (HFE), the European Federation of Pharmaceutical Industries and Associations (EFPIA), the European Cancer Patients Coalition (ECPC), the European Patients Forum (EPF) and the European Public Health Alliance (EPHA) were all potential partners in the fight against chronic diseases.

## **5. Engagement with IDF Global as one of the 7 regions of IDF**

Since the change of the Articles of Association of IDF Global in Cape Town 2006, the Chairs and Chairs-elect of all the Regions are members of the Executive Board of IDF Global.

The Chair of each Region is also a member of the Board of Management of IDF Global.

The regional managers meet once a year and have succeeded to forward recommendations to the Executive Board. The meeting in 2008 was held in Copenhagen and some of the recommendations were:

1. to start working on an IDF Handbook that can be used by staff and volunteers within the organization
2. to change the name of the function of regional office manager into regional manager
3. to increase the level of (financial) support to the 7 regions of IDF Global
4. to have regional offices in fixed places

## **6. Sub- regional Activities**

IDF Europe has a number of sub regional groups which meet to discuss issues affecting particular countries in IDF's wide-ranging European region. These groups are as follows:

Nordic Countries – includes Denmark, Sweden, Norway, Iceland, Faroe Islands and Finland. The last meeting was held from 28 – 31 August 2008 in Stockholm, Sweden.

Diabetes Experts' Panel from Accessing Countries (DEPAC) – includes Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia, Slovenia. The last meeting was held from 1-3 May 2008 in Vilnius, Lithuania.

Central European Countries (CEC) – includes Albania, Bulgaria, Croatia, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Macedonia, Poland, Romania, Serbia, Montenegro, Slovakia, Slovenia and Turkey. The last meeting was held from 19-20 October 2007 in Danisovce, Slovakia



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Eastern European Countries (EEC) - includes Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Ukraine, and Uzbekistan. The last meeting was held from 13-15 June 2008 in Issyk-Kul, Kyrgyzstan.

## **7. Other initiatives**

### Diabetes Prevention Forum (DPF)

The Diabetes Prevention Forum is an exciting initiative of IDF Europe. Originally formed as Gluco-forum, the group broadened its remit from just pre-diabetes to all aspects for prevention and changed its name to Diabetes Prevention Forum in 2008. A group of eleven experts in diabetes education and prevention provides information and guidance on the way forward in prevention of diabetes. With the growing rise in type two diabetes, particularly in younger populations, the group provides valuable insight and guidance for both healthcare providers and the general public.

In addition the group is actively involved in supporting the IMAGE project as the principle partner responsible for the widespread communication of the projects progress and results. IMAGE is an EU funded research project which will develop evidence based guidance and a new curriculum and training program for dedicated prevention managers who will be active in creating locality based diabetes prevention programs across Europe.

### World Diabetes Day 2007

IDF Europe has organised World Diabetes Day 2007 in Strasbourg in the European Parliament. Together with FEND, ISPAD, EURADIA and some of our Corporate Partners IDF Europe managed to bring together 16 children and their parents or guardians from as many European Countries. The theme for the Celebration was Children and adolescents with diabetes, with a focus on schools. In 2008 it was decided that the celebration will again take place in Strasbourg, focusing on children and adolescents and sport.

### Newsletter and Diabetes Voice

The IDF Europe newsletter is another useful tool for communicating with the national member associations, updating them on recent activities in Europe, sharing useful information and 'best practice' across different countries and requesting support for upcoming and ongoing IDF Europe initiatives. The newsletter is produced and distributed approximately every 3 months.

Diabetes Voice, the official publication of IDF Global is also published in Russian as of 2007 and will be available in an electronic form via the website of IDF Global and IDF Europe.



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### Office IDF Europe

The Office of IDF Europe (Lex Herrebrugh, Regional Manager and Lala Rabemananjara, assistant to the RM) facilitated the activities of the Federation. Besides these activities of the Federation the necessary contacts were maintained with other Non Governmental Organizations, mostly based in Brussels, in order to follow up on activities that were related to the European Union (Written EU Parliamentary Declaration, Vienna Conference, EU

Platform on Diet, Health and Physical Activity) and regular contacts with the Corporate Partners were scheduled. As of February 2007, Cristian Andricu was hired as the Association Development Officer, and is based in Romania.

The office was assisted by five external consultants (Anja Strootker, Karoline Lenaers, Debra Lord, Louise Fox and Kellie Atkins) who, with the financial support of some of our Corporate Partners, were able to assist on EU Affairs, Diabetes Prevention Forum activities and the European activities that were directly related to IDF Global's mission to celebrate World Diabetes Day each year.

### Finances

During the General Assembly in St. Julians, Malta, 21 September 2008, the financial report 2006 was presented separately. IDF Europe ended the year 2007 with a positive balance of € 18.640.

The conclusion is that the financial situation of IDF Europe is stable and that we can expect a balance of income and expenses in this triennium.

IDF Europe receives a yearly payment of € 25.000 from IDF Global and fees from its Corporate Partners. We are also very happy with the direct support from a small number of member associations, and we hope that in future more member associations will support IDF Europe directly for its increasing activities.

### Partnerships

From the former paragraphs it is apparent that IDF Europe's activities are very much dependent on the support of our member associations and Corporate Partners. IDF Europe did not receive any financial support from governments nor from the European Union.

That means that without the (financial) support from our Corporate Partners (from their headquarters as well as from their affiliates) we would have been extremely restricted in our activities.



At the start of 2008 the following 14 companies were Corporate Partners of IDF Europe (in alphabetical order):

AstraZeneca, Bayer, Bioton, Eli Lilly, GlaxoSmithKline, LifeScan, Medtronic, Merck Sharp & Dohme, Novartis, Novo Nordisk, Pfizer Europe, Roche Diagnostics, Sanofi Aventis and Servier.

Since the General Assembly in Dublin in September 2007 two meetings with the Corporate Partners were held: 8 February 2007 and 19 September 2008. The next meetings are planned in February 2009 and October 2009. We are all of them very thankful for making our activities possible.

### **Closing remarks**

From the previous paragraphs we conclude that 2007-2008 was once again an extremely energetic and positive year.

The Board of IDF Europe wants to say “thank you” to all those who have worked so hard (volunteers and office) for the benefit of all people with (pre-) diabetes in Europe.

The Board of IDF Europe