



## National diabetes programmes and the road towards an EU Diabetes Strategy

11 October 2011, European Parliament, Brussels

### *Meeting Report*

The **EU Diabetes Working Group (EUDWG)** met in the European Parliament, Brussels to discuss the current status of National diabetes programmes in the EU and the political action towards an EU Diabetes Strategy.



The meeting was hosted by the **EUDWG Co-Chair Baroness Sarah Ludford, MEP (ALDE, UK)** and organised by the **European Coalition for Diabetes (ECD)**. Among the participants were the EUDWG Co-Chairs - **Christel Schaldemose MEP (S&D, Denmark)** and **Simon Busuttil MEP (EPP, Malta)**. The meeting was attended by other MEPs with an interest in health issues and particularly diabetes, by the Danish Health Attaché Kåre Geil, and by representatives of the pharmaceutical industry and other NGOs.

The invited speakers were **Dr Jelka Zaletel**, Co-Chair of the National diabetes programme at the Slovenian Ministry of Health and **Dr Isabel de la Mata**, Principal Adviser with special interest in Public Health at the European Commission, DG SanCo.

Following the introduction, Baroness Sarah Ludford MEP, reminded participants of the pressing need for a targeted EU diabetes strategy – because of the huge impact on individuals, society and economies (it takes up to 10% of health care budgets) around 30 million people have diabetes in the EU. An EU strategy already exists for cancer and for CVD. All states would have their national plans and ensure best practice is shared.

In September there was the first ever UN Summit on NCDs including diabetes, with a UN Resolution. There is also a call in the European Parliament for Increased research, prevention, and cure and better treatment of diabetes.

Dr Jelka Zaletel presented the National diabetes programme from Slovenia - **“Do's and Don'ts of National Diabetes Programmes: the model of Slovenia”** prepared with Milivoj Pilletic, MD.

Dr Zaletel spoke about the complex factors influencing the development of a National diabetes programme (NDP), as she called them “a messiness of life”. The work on the NDP started in Slovenia in 1989, following the St. Vincent Declaration and resulted in an “office-made” NDP that was never implemented. At that time the public institutions and other stakeholders were not ready to cooperate in developing an implementable NDP. The new “era” started in 2006, when a working group (WG) was organized at the Ministry of Health after input from a senior diabetologist and the President of the patients’ association. In 2006, the first WG was formed with the current Minister of Health – Dorijan Marusic as Chair, taken up shortly after by Vesna-Kerstin Petric.



Another breakthrough came in 2008 from the Diabetology Association that based its activities on partnership, transparency, complementarity and respect. It focused its programme on improving the quality of care within specialist teams, improving communication with general practitioners (GPs) at a national level. Dr Zaletel highlighted that the driving force for the discussions around the NDP was “the passion to fight diabetes”, with the motto **“One cannot change the world, two can!”**

During 2006-2008 the various stakeholders found the best approach to address the burden of diabetes.

The first Slovenian NDP was developed for a 10-year period. It was based on the concept of the Chronic Care Model and studies of the European Observatory on Health System and Policies. It included the requirement to establish Action Plans every 2 years. The timeline of the Slovenian NDP (2009 to 2010) included periods of draft preparation, consultation, inclusion of payer as stakeholder, public debate, presentation to the Health Council and eventual adoption by the Government.

At this point Dr Zaletel stressed that the NDP was a 'side product' of the partnership, respect and trust, that developed between the stakeholders.

The **Action Plan for 2010-2011** has already had several results:

- a strategy for taxation of sugar added to drinks and other unhealthy food
- at NIH – diabetes became top three
- restructuring of primary care - model practices: prevention, early diagnosis, early treatment
- a competency profile for diabetes registered nurses
- development of guidelines and models of care
- development of diabetes registries
- dispensing prescriptions
- involvement of patients: driving license law, model practices, Dia-phone, ...

Dr Zaletel mentioned the importance of the complementarity of the NDP with other diabetes related processes and that it is crucial to integrate diabetes in other healthcare areas. An important aspect is the “zero cost” concept for the NDP, raising other drivers for its implementation, making it efficient, effective and affordable.

However, there were some failures including clinical standards development, joint projects, bad reporting, and human resource planning (combining employers and activists). In addition she mentioned the need to appreciate the ‘languages’ and ‘cultures’ of the different stakeholders, (nurses, GPs, specialists, pharmacists, payers, public institutions, and people with diabetes. to ensure that all felt empowered to deal with diabetes. Moreover, leading such a profound change within the healthcare system has many components of a social movement, and she cited Helen Bevan from the NHS Improvement Agency. The process of change is not linear and that is simply the nature of the change. The leadership of that complex process is “accepting the responsibility for enabling others to achieve the common purpose under conditions of uncertainty”, she cited Marshall Ganz.

The next challenge was to ensure sustainability while maintaining flexibility, fear of the private sector, initiating joint projects, how to deal with unmet expectations, how to develop network leadership and mostly, how to keep the passion of the WG to make things happen.

Dr Jelka Zaletel concluded her presentation with a statement from Steve Jobs: '**Work hard and make it simple**'.

The second speaker, **Dr Isabel de la Mata**, spoke on behalf of the European Commission (COM) about the "**Reflection process on chronic diseases at EU level**". Dr de la Mata explained the COM approach to diabetes. She mentioned that the COM Health Strategy and Health Programme have changed since 2003 from a vertical to a horizontal approach, thus focusing on groups of diseases rather than individually. Dr de la Mata said that the same approach was promoted during the **Conference on Innovative Approaches to Chronic Diseases** in 2010. She noted that non-communicable diseases (NCDs) and chronic diseases (CDs) were not always the same thing.

Dr de la Mata presented the Commission's four principles for responding to the challenges of chronic diseases: **integration** – working on a group of diseases is more efficient in times of economic crises; **work in a practical way**; **innovation** – not only technological but also social innovation; **transparency** – integrate all stakeholders and involve people from outside the healthcare sector (education, transport, etc.).



Dr de la Mata informed participants that the **Reflection process on chronic diseases at EU level** had been launched in the European Council on 10 October 2011 and will most likely end in 2013. She expressed her concern about the low budget available for the COM to work on NCDs and CDs but she was optimistic that this situation would change. In addition, Dr de la Mata said that the COM was addressing chronic diseases horizontally, and by addressing the main health determinants: tobacco, nutrition, obesity, and physical activity.

## Discussion

The meeting concluded with a discussion between EUDWG Co-Chairs, ECD representatives, the Danish Health Attaché and other participants.

Following Dr de la Mata's speech, **Baroness Sarah Ludford MEP (ALDE, UK, EUDWG Co-Chair)** stressed that addressing health determinants does not help people with type 1 diabetes.



**Christel Schaldemose MEP (S&D, Denmark, EUDWG Co-Chair)** intervened and said that although the COM seemed to be committed to take action at EU level it was constantly delayed. She said that when it came to taking action, "it is not about either/or but about both/and." In addition, she asked Dr de la Mata why the COM not does something about diabetes since there are already EU strategies for individual chronic diseases such as cancer. By spreading attention across a group of diseases little will be achieved by the COM in the area of CDs. Finally she said the European Parliament and the European Council would continue to put pressure on the COM to develop disease specific strategies.

Ms Schaldemose also addressed a question to Dr Zaletel, asking "what can be done by the EU to help national diabetes programmes?"

In response, **Dr Jelka Zaletel** expressed her enthusiasm about having the COM as stakeholder in the Slovenian National diabetes programme. She said that direct communication between the Steering Group on NDP and the COM would help to understand what happens at EU level and how to leverage/coordinate future actions on diabetes.

**Simon Busuttil MEP (EPP, Malta, EUDWG Co-Chair)** thanked the speakers for their contributions and mentioned that common efforts should be focused on achieving added value by getting increased cooperation in the EU, apart from the Member States' initiatives. Further, mentioned the recently tabled European Parliament Resolution on NCDs and surrounding debate.

Dr Busuttil added that the EUDWG was currently preparing a request for a Diabetes Resolution and, although some resistance was expected from the COM, the ECD and the EUDWG would continue seeking to have a Diabetes Resolution adopted by the European Parliament. He mentioned that the EUDWG would work on gaining more support from several Members of the European Parliament. Finally, he highlighted that the upcoming EU Presidencies - Denmark and Cyprus – were very keen to address diabetes and a future Diabetes Resolution within their agenda.

**Anne Marie Felton, President of the Foundation of European Nurses in Diabetes (FEND) and Vice-President of the International Federation of Diabetes (IDF)** talked about the outcomes of the **UN Summit of NCDs** from September 2011, which she had attended. She expressed concern that no discussion was carried out during the Summit and thus the opportunity to achieve tangible results in the fight against NCDs was lost. She said that each Member State participating in the Summit had read a 3-minute statement with no room for constructive debate.

Ms Felton stressed that the horizontal approach in fighting NCDs was in fact damaging the major chronic diseases. This was seen during and after the UN Summit on NCDs, which lacked of concrete targets and timelines.

**Dr de la Mata** took the floor and spoke about the current EU Health Programme that has only EUR 15 million per year available to develop an efficient strategy. Therefore, unless a better solution is available, the COM will work horizontally. Dr de la Mata also said that the COM took note of the Danish EU Presidency's commitment for diabetes but she remained sceptical that much could be done in 6 months.

**Christel Schaldemose MEP** mentioned that, when thinking about dealing with chronic diseases "it is not only a question of money, but of finding the right way to cooperate."

**Kåre Geil, Health Attaché at the Danish Permanent Representation to the EU**, spoke about the pressure he felt for taking action on diabetes during the Danish EU Presidency. He said that it was up to the new Danish government to fix the priorities for the Danish EU Presidency. He added that, although the priorities are not yet set, they will be defined soon and the Danish government is aware of the importance of CDs. However, the COM will open a public consultation on the Reflection process on CDs. Therefore, one of the priorities for the Danish EU Presidency was to work on health issues together with the European Parliament.

**Prof Andrew J. M. Boulton, President of the European Association for the Study of Diabetes**, expressed his "high hopes" of the Danish EU Presidency. Further, he said that there was a need to raise the profile of



diabetes, especially type 2. He highlighted that the life expectancy for people affected by type 1 and type 2 diabetes was worse than for the most cancers. Therefore, when addressing the need to develop an NDP one should consider the necessity of data. Prof Boulton concluded stressing that it was vital to assess the NDPs by the systems.

Ms **Felton** replied that the 'Policy Puzzle' issued by the IDF European Region and FEND addresses the status of NDPs in Europe. The 3<sup>rd</sup> edition would be published in November 2011 on the World Diabetes Day but she said that the picture does not really look good and only few European countries have developed and implemented NDPs and there is still a huge work to be done on advocating for NDPs.

**Prof Philippe Halban, Chairman of EURADIA and Co-Chair of ECD** intervened with a question for the COM representative Dr de la Mata. He asked why the COM does not seem to have any sense of urgency for taking action on chronic diseases, when it came to infectious diseases, such as AIDS or H1N1, the COM was very quick in responding with immediate action. But diabetes, although not an infectious disease, was also an increasing epidemic. Why does the COM insisting on having a horizontal approach and why does it need so long (until 2013) to finalise the reflection process on chronic diseases.

Further, **Mr Chris Delicata, President of IDF Europe and Co-Chair of ECD**, added that he fully agreed that a horizontal approach would not work. He said that the diabetes epidemic was growing fast and the COM intentions are not at all encouraging. He stressed the importance of taking action instead of talking "again and again" about how one should take action.

In response to the question of Prof Halban, **Dr de la Mata** said that the COM had a mechanism in place to take action to fight infectious diseases, but this was not yet the case for chronic diseases. She added that a sense of urgency exists also for chronic diseases, but the procedure includes a public consultation and this is why it may take longer to achieve tangible results. Dr de la Mata concluded that the COM is repeating "the same thing" (horizontal approach) because it is convinced that this is the right way to act.

Prof Johan Wens, Chairman of PCDE and Co-Chair of ECD, closed the meeting by thanking the speakers and participants for their attendance and contributions.