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Letter From the Chair



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Dear Members.

These past three months have been a very busy period for all diabetes stakeholders, in Europe and beyond.

Let's start with the good news! Thanks to the hard and truly effective work of our members, and in particular FEND and IDF Europe, we now have a Written Declaration of Diabetes from the European Parliament with a strong endorsement from the EU Health Council, promoting "...healthy lifestyles and prevention of type 2 diabetes". The budget for FP7 has finally been approved and although much reduced will still allow for many of the original programmes and tracks to be funded. EURADIA has taken a strong stand in its Position Paper that has been sent to all relevant European decision makers, parliamentarians and civil servants alike, insisting on the need to separate "diabetes/obesity" in the FP7 document. Thank you for your support in this important endeavour of our Alliance. Last but not least, IDF Global, has forged ahead with its campaign to pass a UN Resolution on diabetes, with the formal launch of "Unite for Diabetes" during the ADA meeting in Washington. This campaign has the active support of the Alliance and its individual members.

Alas, as you may have guessed, there is some (very) bad news too! The programme of Community action in the field of health has been subjected to savage budget cuts (not to say sabotage) resulting in removal of specific actions to tackle individual diseases, including diabetes. As you will read in these pages, some of our members have already reacted in the strongest terms and the Alliance is standing by to assist in any way possible. All diabetes stakeholders will suffer if these cuts are confirmed, with devastating consequences across the board, including diabetes research.

EURADIA, through its own actions and through the efforts of its individual members, is helping to reshape the future of European diabetes research. Let the good work continue, but hopefully with time for each of you to enjoy some well-deserved vacation time these coming weeks. That is certainly what I shall be doing!

> Philippe Halban Chair EURADIA

Welcome to new representatives on the Board of EURADIA

EURADIA would like to welcome its new Board Members:

Ms. Gill Bishop, representing AstraZeneca

Global Publications Manager

AstraZeneca 2

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EURADIA key messages – June 2006

- Diabetes in its two major forms is a disease with specific characteristics that demand specific type of research.
- Research on obesity or nutrition alone will not solve the problem of the diabetes epidemic.
- Support for type 1 diabetes research suffers when diabetes and obesity are pooled together since the causes and development of type 1 are different from type 2 diabetes.
- The wording of the proposals for FP7 should be changed to "diabetes, obesity" and funds should be allocated separately to both diseases, or combined with a common budget that is increased accordingly.



Position paper

EURADIA issued in May 2006 an official "statement on diabetes research in FP7 with recommendations for identification of diabetes as a unique disease" – as approved by membership. The Alliance explained its concern that increasingly nutrition and obesity were mentioned in common programmes with diabetes, thereby artificially increasing the apparent budget dedicated to diabetes, and claimed that support for type 1 diabetes research suffered in particular when diabetes and obesity were pooled together since the causes and development of type 1 diabetes were different from type 2 diabetes (the position paper is available under www.euradia.org).

This position paper has been sent to a number of political stakeholders and civil servants: health-related attachés and counsellors from the 25 Permanent Representations to the European Union; the cabinets of Commissioners Potočnik and Kyprianou; the Directors-General, the Directors, the Heads of Unit and a number of relevant experts such as policy and project officers within DG-RTD, DG-SANCO and DG-JRC; Members of the European Parliament Environment, Public Health and Food Safety Parliamentary Committee (ENVI) and the President and Vice-Presidents of the Health and Consumer Intergroup. More than 250 key opinion leaders received an email with our position paper. On top of that, a number of key MEPs received a paper version in their letterbox in the European Parliament.

Fact sheet on diabetes research in Europe

EURADIA has been preparing a short fact sheet on diabetes research in Europe which aims at being as accurate and objective as possible (see below). Please feel free to contact the EURADIA secretariat if you are aware of additional figures or new sources of information. Thank you for your help!

Foreword

Diabetes is a real epidemic. 25 million Europeans have the disease and this figure is expected to double by 2025. Many of these people are not even aware of their condition (up to 50%). It is estimated that the indirect costs (costs of lost production) may be as much as five times those of the direct costs which already represent more than 7% of total health expenditures. Diabetes is highly ranked among the leading single causes of death, but one has to keep in mind that the actual number of deaths for which diabetes was a contributing factor, is several times larger.

Diabetes research in Europe is under-funded compared to the USA. Support for diabetes research from the European Commission has significantly increased during FP6, but still represents only 3% of the NIH diabetes spending over the same period.



Figures

	EU (25)	USA	World
Prevalence	25 million (2003 - IDF Diabetes Atlas)	20,8 million 6,2 million undiagnosed (2005 - NIDDK)	194 million (2002 - IDF Diabetes Atlas)
Mortality	>95000 (1) 5th leading cause (F) 10th leading cause (M) (1998 - Eurostat))	>73000 ⁽²⁾ 6 th leading cause (2002 - NIDDK)	2,9 million ⁽²⁾ 5 th leading cause (2000 - Diabetes Care)
Direct costs	€50 billion ⁽²⁾ (2005 - IDF/FEND)	\$92 billion (2) (2002 - NIDDK)	
Research funding	€25 million (3) (EC) (2006 - EC)	\$1 billion (2) (NIH) (2005 - NIH)	

⁽¹⁾ Average - 381971 persons died of diabetes between 1994 and 1998

EC: European Commission

FEND: Federation of European Nurses in Diabetes

IDF: International Diabetes Federation

NIDDK: National Institute of Diabetes and Digestive and Kidney Diseases

NIH: National Institutes of Health

F: females

M: males

Sources:

The Burden of Mortality Attributable to Diabetes. Realistic estimates for the year 2000. Diabetes Care 28:2130-2135, 2005

http://ec.europa.eu/comm/health/ph_information/dissemination/diseases/diabetes_en.htm

http://www.eatlas.idf.org/

http://diabetes.niddk.nih.gov/dm/pubs/statistics/index.htm#14

http://www.nih.gov/news/fundingresearchareas.htm

http://www.fend.org/news_assets/DiabetesReport.pdf

http://www.fend.org/news_assets/diabetes_eu_policypaper.pdf

http://cordis.europa.eu/lifescihealth/major/cardio.htm

A special thank to Stefan Björk, François Camus, Anne-Marie Felton and Nathalie Vercruysse for their contribution to this fact sheet.



⁽²⁾ Values per year

⁽³⁾ Average value per year - ~ €100 million invested in research programmes between 2002 and 2006 (FP6)

EU news

Written Declaration on Diabetes

In April 2006, the European Parliament adopted by absolute majority a Written Declaration on Diabetes. A press conference was held in the European Parliament on this issue on 19 April 2006. The declaration, tabled



by John Bowis, MEP (photo), together with his colleagues Georgs Andrejevs, Dorette Corbey and Karin Sheele, urged the Commission and Council to prioritise diabetes in the EU health policy, to encourage Member States to develop national diabetes plans and calls to develop an EU diabetes strategy on the basis of an EU Council Recommendation on diabetes prevention, diagnosis and control. The experts, Dr. Michael Hall, Board Member of IDF Europe, and Anne-Marie Felton, Chairman of FEND also attended the conference. They both welcomed the declaration and pointed out that diabetes is a serious and costly problem. During the press conference EU investment issues were raised and it was suggested that the EU could do a lot more in this area. It was stressed that more money should be allocated to research; the amount of eighty million for four years (currently amount allocated) was considered as "tiny". In summary the Parliament calls for: research, testing, early diagnosis, treatment, education, support for the families, promotion of healthy life style and an EU framework for diabetes.

Written Declaration on Diabetes

The European Parliament,

- having regard to Rule 116 of its Rules of Procedure,
- A. whereas diabetes is a serious chronic and progressive condition affecting over 25 million people in the EU, with an expected increase of 16% by 2025,
- B. whereas the serious and costly complications of diabetes include cardiovascular disease and stroke, kidney failure, amputations and blindness,
- C. whereas there are some 60 million people in Europe at risk of developing pre-diabetes,
- D. whereas an EU diabetes strategy would help contain public health expenditure in EU Member

- States, bearing in mind that diabetes complications represent 5% to 10% of total healthcare spending,
- E. whereas the merit of a coordinated EU approach has been demonstrated by the EU Council Recommendation on cancer screening,
- F. whereas the Austrian EU Presidency (2006) is prioritising Type 2 diabetes,
- 1. Welcomes the Presidency's initiative on diabetes;
- 2. Calls on the Commission and Council to:
 - prioritise diabetes in the EU's new health strategy as a major disease demonstrating a significant burden across the EU;
 - encourage Member States to establish national diabetes plans;
 - develop an EU diabetes strategy and draft an EU Council Recommendation for Diabetes Prevention, Diagnosis and Control;
 - develop a strategy to encourage consumption and production of healthy food;
- 3. Instructs its President to forward this declaration, together with the names of the signatories, to the Council and the Commission.

Since April 2006

Diabetes debated at Council meetings

On the 25th and 26th of April, the EU's 25 Health Ministers gathered in Vienna for an informal Council at the invitation of the Austrian Presidency. One of the two topics debated was diabetes. The Ministers discussed a strategy for preventing diabetes and promoting healthy lifestyles in the EU. The meeting in Vienna highlighted the need to exchange best practices, enhance networking, improve controls on symptoms of the disease and draw up regular reports on its evolution in the EU.

This meeting was followed by a formal meeting on 1-2 June on "promotion of healthy lifestyles and prevention of type 2 diabetes". Among other important issues, the Council acknowledged "that further research in Europe on the health determinants for combating the risk factors for diabetes could make a positive contribution to addressing the disease in the future" and invited "the European Commission to support, as appropriate, Member States in their efforts to prevent diabetes, and to promote healthy lifestyle by: [...] facilitating and



supporting European diabetes research in basic and clinical science and ensuring the wide dissemination of the results of this research across Europe."

(Press release available under:

http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/lsa/89847.pdf)

Programme of Community action in the field of health refocused - specific action to tackle individual diseases no more included

On 24 May 2006 the scope of the health programme 2007-2013 of the Commission was refocused due to resource constraints. "The final budget for health action was settled at € 365,6 million, i.e. approximately one third of the budget initially foreseen in the Commission proposal of April 2005." There will be only "three broad objectives: to improve health security; to promote health to improve prosperity and solidarity; and to generate and disseminate health knowledge". "This modified proposal does not include a specific action to tackle individual diseases", in contradiction with the Commission's original proposal which was further strengthened by the European Parliament.

(Source: COM(2006) 234 final

http://ec.europa.eu/health/ph_overview/Documents/com_20060524_en.pdf)

Following the outcome of the EU Health Council, IDF Europe and FEND have referred to the Commission's amended proposal for the EU Health Action Programme as "blatantly contradicting" the Council's Conclusions and have expressed their utter dismay at "a watered down proposal based on the excuse of limited resources". IDF-European Region and FEND, together with a number of other European patient organisations, will now be calling on MEPs to reject the Commission's amendment during the second reading of the proposal later this year.

New Health-EU portal

On the 11th of May, the Commission launched its Health-EU portal. You can access it via this link: http://ec.europa.eu/health-eu/index_en.htm

Court of Auditors' opinion on FP7

According to the European Court of Auditors which released its audit report at the end of March, the European Commission's proposal on rules for participation for the Seventh Framework Programme (FP7) "misses [an] opportunity for a radical change". The main weaknesses in the Commission's proposal concerned the transaction cost per euro spent,

excessively cumbersome grants and a lack of flexibility. "Whilst it is recognised that a certain degree of complexity is inevitable, the Court considers that the Commission proposal misses the opportunity to bring about radical changes to the administrative and financial rules for the Seventh Framework Programme", stated the Court's opinion. The paper calls for recognition that scientists often need to react quickly to external and internal changes during the lifecycle of a project, through the awarding of increased decision-making powers to the project coordinator.

Parliamentary action on FP7

The European Parliament's Industry, Research and Energy (ITRE) Committee has adopted compromise amendments on the budget for the Seventh Framework Programme (FP7) and the breakdown of the funding. The Committee also clarified which areas will not receive funding for ethical reasons. MEPs brought the research programme in line with the agreement on the Financial Perspectives for 2007 to 2013, reducing the budget from the proposed 72,726 billion euro to 50,524 billion. The ITRE Committee's version lists the following areas of research as not supported: human cloning; heritable modifications of the human genome; and production of human embryos solely for stem cell procurement. It added that: "Research on the use of human stem cells may be financed under this framework programme, depending both on the contents of the scientific proposal and the legal framework of the Member State(s) involved." In addition, the Committee agreed that researchers and institutions must be subject to strict licensing in accordance with the legal framework of the countries involved.

In the Plenary Sessions in Strasbourg of the week of the 12th of June, the European Parliament has adopted the report outlining the FP7 by an overwhelming majority. This endorses the structure of FP7. The report now gives broad support to the European Commission's proposed work programme, which will have a budget of EUR 50,521 billion. Although EUR 50,521 billion is lower than both the Commission and many MEPs wanted, it is substantially higher than the EUR 16 billion budget of the current Framework Programme. MEPs were happy with the nine thematic areas outlined by the Commission. The votes on amendments referring to stem cell research were extremely close. In the end, the MEPs voted by a majority of just 25 votes to follow the line suggested by the ITRE, i.e. research on the use of both adult and



embryonic human stem cells may be funded by FP7, subject to national laws and strict licensing rules. Italian MEP Marco Cappato, who is strongly in favour of stem cell research, described the vote as "a success for a secular and tolerant Europe."

EURADIA Annual Meeting

It is still our intention to hold EURADIA's Annual Meeting in the autumn in Brussels. It is however proving very difficult to find a date allowing for this meeting to be hosted by an MEP in the European Parliament. This period is, furthermore, particularly busy for diabetes stakeholders. The secretariat will contact the EURADIA membership as soon as we have a solution.

