



Diabetes: Europe rising to the research challenge

Highlights from the jointly organised major stakeholders' conference held on 12 November 2004 in Brussels by invitation of the European Parliament

The conference was jointly organised by the European Association for the Study of Diabetes and the European Commission for Research and Health. The 'challenges' in diabetes research were the theme throughout this landmark conference, along with proposals for ways in which they could be overcome. The prospect of increasing numbers of people with

diabetes and its complications over the next half-century and the impact this will have on our society were repeated by 'every sector that counts' from research, the health professions, industry, national governments, non-governmental organisations, representatives from the European Union and, of course, people with diabetes.

Dr Octavi Quintana Trias (*European Commission DG-RTD Director, Health Research*) opened the meeting on behalf of the Health Commissioner. All of the stakeholders, he said, were represented at the conference: the brains and the power in diabetes research, for which the European Commission (EC) was acting as facilitator and catalyst.

Diabetes affects 2.3–10.1% (more than 18 million) of European Union (EU) citizens and by the year 2030 this will rise to at least 26 million (5.9%). The importance of this disease to Europe means that all stakeholders – people with diabetes through to industry – should act together to bring it to the attention of decision makers.

Professor Reinout van Schilfgaarde (*Advisor to The Netherlands Health Minister, Ministry of Health Welfare and Sport*) assured the audience that diabetes was intended to be a priority for the EU sixth framework research programme (FP6). Type 1 and type 2 diabetes had similar severe consequences and the incidence of both was increasing. Diabetes is responsible for four of each 10 myocardial infarcts (MIs) and for five of each 10 foot amputations, and is the leading cause of new blindness.



Among the speakers at the conference were (left to right): Alain Vanvossel (RTD Health), Edwin Gale (Editor-in-Chief, *Diabetologia*), Lars Rebieen Sørensen (Novo Nordisk), Allen M Spiegel (NIDDK), and John Bowis (MEP)

Professor van Schilfgaarde enthusiastically supported the translational approach whereby fundamental research into pathophysiological mechanisms of diabetes had led to practical population-based studies and produced a 'paradigm shift' in that treatment was now prescribed on a rational basis rather than by 'endless trial and error'.

Continuing the theme of how and where to direct diabetes research, Professor Ele Ferrannini (*President, European Association for the Study of Diabetes [EASD], Italy*) under-

lined that diabetes is an epidemic in many parts of the world, where the disease is driven by obesity – itself an epidemic everywhere. Diabetes is chronic, systemic, mostly irreversible, and is hard to manage, disabling and costly. Professor Ferrannini asked: 'Why is research in diabetes needed?' It is a disease with multifactorial origins and an unknown aetiology, is a continuing genetics nightmare, and has a complex pathophysiology. Available treatment is generally unsatisfactory.

Types of diabetes research being



undertaken vary from pathology of the human islets of Langerhans to clinical co-morbidities such as hypertension. Never had so much research been carried out in so many countries – in academic centres and by industry. Drug targets were diverse: from new insulins and glucagon-like peptide 1 analogues to stem cells. The clinical ramifications of diabetes were widespread: from endocrinology to surgery and internal medicine. The leading status of Europe within the diabetes research community was confirmed by the highest attendance at a scientific diabetes conference recorded at the EASD in Munich in 2004 with 12 500 participants. Professor Ferrannini concluded that Europe was rich in the necessary intellect and goodwill to lead the research into diabetes.

The rise of type 1 diabetes and type 2 diabetes: a challenge for European research

Professor Pierre Lefèbvre (*President, International Diabetes Federation [IDF], Belgium*) discussed the burden of diabetes in the world. The number of people with diabetes worldwide was currently close to 200 million and projections indicated that this may increase to over 300 million by 2025. Type 1 diabetes was increasing in incidence (a cause of concern) while there was also an increase in the longevity of those affected (a cause of satisfaction). Areas being investigated in type 1 diabetes were exposure to viruses, milk proteins and environmental factors. Type 2 diabetes encompassed around 90% of all diabetes and was now being seen in younger people; there was a clear link with obesity caused by changes in lifestyle.

Professor Gyula Soltész (*University of Pécs, Hungary*) described the rise of type 1 diabetes. Type 1 was still the dominant form of diabetes in the young and this illness affected the whole family, with

a loss of normal childhood and loss of the right to be carefree and free of pain. Type 1 diabetes was a chronic illness that affected you every day for the rest of your life; there was currently no known cure. Despite the fact that several genetic and environmental risk factors had been identified, the mechanism of this disease was largely unknown.

Professor Daniel Pipeleers (*Free University Brussels, Belgium*) highlighted the problems for the investigator in the 'Promise of islet research in the prevention and treatment of type 1 diabetes'. He described the way in which a research network could support the research and development platform for multi-centre clinical trials, reference centres and the bio-industry. Research areas, he said, must be driven by medical and scientific objectives. The financial resources for trials in Europe were almost non-existent compared to the USA – and in islet research the main funding in Europe comes from the USA. In Europe an excess of paperwork reduced creativity, which made collaboration with the USA attractive. Europe should learn from the example of the USA on how to manage research.

Professor David R Matthews (*Oxford Centre for Diabetes, UK*) presented the disturbing 'Emergence of type 2 diabetes in the young'. Type 2 diabetes was previously associated with overweight middle-aged adults, but was now being increasingly seen in children. The increase in childhood obesity was driven by more dietary fat and calories and less physical activity. Today's relatively cheap and tasty food was contrasted with the more plain food served in the past. This desire for 'junk' food was driven by television advertising aimed at children.

The consequences of type 2 diabetes in young people were increased renal disease and

retinopathy developing at an earlier age. Treatment options for type 2 diabetes at such an early age were limited with many of the adult treatments being ineffective.

Professor Marja-Riitta Taskinen (*University of Helsinki, Finland*) discussed 'Prevention and treatment of type 2 diabetes'. Type 2 diabetes was previously considered to be a mild disease in the elderly; in fact, 80% of people with type 2 diabetes died from cardiovascular disease (CVD). Type 2 diabetes is life-threatening and had become so by a combination of lifestyle and genes; the genes that had helped when the environment required physical exertion to survive had become deadly in today's sedentary environment. This 'toxic' environment should be a target for action at the EC level.

Several oral antidiabetic agents with metabolic effects were available but none was completely successful. Clinical studies are at present testing new compounds targeted at rescuing deteriorating beta cells, improving lipids, and/or preventing vascular disease in addition to maintaining blood glucose at normal range.

Strategic diabetes research topics in Europe were reported by Professor Jaakko Tuomilehto (*Finnish National Public Health Institute, Helsinki, Finland*). Strategic research planning is needed for diabetes which, he emphasised, was not a rare condition. As there was no cure, people with diabetes must find ways of dealing with the disease. However, lifestyle programmes had been found to be highly beneficial (as demonstrated by the Diabetes Prevention Program), although some of these programmes had to be discontinued due to insufficient funding. Professor Tuomilehto noted that in FP6, although genetic research was heavily featured, funding for research into living conditions had decreased. Genes are important –



especially in type 1, but also in type 2 – but he pointed out how little progress had been made in the area. An example of how research into type 2 diabetes is needed can be illustrated by the fact that the majority of patients admitted to hospital with a first MI are already found to have abnormal glucose tolerance – indicating that the disease had already progressed. The implications of delaying research into this disease and its causes will have important consequences.

Health care professionals and patients confronted with diabetes

Mrs Anne-Marie Felton (*Chairman, Federation of European Nurses in Diabetes [FEND], UK*) began her talk on ‘How nurses were impacting on the diabetes epidemic’ by congratulating the meeting organisers on their foresight in placing her presentation between the scientific part of the programme and the presentation by two people with diabetes – reflecting the place of the nurse as the facilitator of teamworking, bringing the results of research directly to people with diabetes who are the key carers and managers of their condition.

FEND was at the forefront of gathering evidence to demonstrate the importance of the work of the diabetes specialist nurse on the outcome of care for people with diabetes. In the past year, the first FEND Professor of Diabetes Nursing had been appointed at the University of Uppsala. The universities of Uppsala, Surrey and Barcelona were collaborating on a course in specialist diabetes nursing (ENDCUP). A new nurse-led journal, *European Diabetes Nursing*, had been launched on the initiative of FEND. Nurses were now working in all areas of diabetes, in clinical, research, education and at national and international levels influencing these critical domains.



Twin sisters with type 1 diabetes, Joke and Liesje De Gucht from Belgium, described the impact of diabetes on their lives from the time of diagnosis onwards

The reality of living with diabetes was brought home to the audience during the final session of the morning. Twin sisters with type 1 diabetes, Mss Joke and Liesje De Gucht from Belgium, described the impact of diabetes on their lives from the time of diagnosis onwards. One sister had been diagnosed at the age of 11 while the second was diagnosed several years later after continuing and constant tests.

Despite availability of tests to diagnose the disease there is still no treatment to stop the development of type 1 diabetes in people with a high risk for the disease. The twins described a life in which all activities from meals to exercise require constant attention and the perpetual worry about hypoglycaemia. The plea of the sisters was that a cure should be found for this disease.

The indispensable means to combat the disease

Mrs Zsuzsanna Jakab (*Secretary of State, Ministry of Health, Social and Family Affairs, Hungary*) spoke about ‘The costs of diabetes in Europe’. Cost was not only financial, but included impact on the family and all aspects of society. Complications are costly to everyone – the person with diabetes, their families and society (increased risk of CVD, blindness, kidney failure, gangrene and peripheral limb amputation).

The chronic nature of diabetes makes the health care of people with diabetes at least 2.5 times more costly than that of people without the condition, and the high costs are mainly in type 2 diabetes. There are direct costs of health care, but also the indirect costs of loss of productivity, early retirement, premature death or long-term illness; these are aside from the impact on quality of life.

To reduce the impact of diabetes in Europe, measures are needed now for surveillance, prevention and control. A starting point was the 2004 EU Workshop in Dublin ‘Towards a European Framework for Diabetes Prevention and Care’, the St Vincent Programme and Declaration of the WHO that put diabetes on the agenda of the forthcoming EU Council. Diabetes is a health policy priority in our ageing population: a full and healthy life is possible with diabetes, but raising awareness is needed to ensure diabetes is a priority in public health and research.

Dr Allen Spiegel (*Director, National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], USA*) presented ‘The North-American experience’ and gave an insight into the way in which diabetes research funding is handled in the USA. The annual budget for diabetes research at the



NIDDK in the past 10 years has doubled from \$200m in 1994 to \$400m in 2004 (of that 75% goes to type 1). The progression of type 1 diabetes and strategic planning of research to impact at each stage was illustrated by a timeline showing type 1 diabetes from the early stages up to disease onset – and by the studies funded by NIDDK.

NIDDK actively encourages industrial partnership and an example of such collaboration – the Beta cell consortium – has the mission to ‘facilitate interdisciplinary approaches that will advance understanding of pancreatic islet development and function’. In type 2 diabetes, funding follows a similar strategy from primary prevention to tertiary prevention and treatment of complications.

Dr Richard Insel (*Executive Vice President of Research, Juvenile Diabetes Research Foundation [JDRF], USA*) discussed the ‘Research opportunities for type 1 diabetes in Europe’. The JDRF is the world’s leading non-profit, non-governmental funder of type 1 diabetes research and has provided more than \$800m since 1970 (\$500m allocated in the last five years). The JDRF collaborates with all diabetes stakeholders, including national governments and other NGOs. Research commitment is directed to translating basic discoveries into therapeutic interventions to cure and prevent type 1 diabetes and its complications.



Richard Insel discussed research opportunities for type 1 diabetes

Internationally, research funding outside the USA doubled in the last five years to about 37% of total present funding. Research is funded in 20 countries and approximately 25% is within Europe. JDRF sees Europe as a good place to invest because it has the research culture, produces cutting-edge science and has the epidemiology expertise to organise clinical trials.

Mr Lars Rebien Sørensen (*President and CEO, Novo Nordisk A/S, Denmark*) demonstrated how ‘Industry is rising to the challenge’ in diabetes research. In response to previous sessions describing rising numbers of people with diabetes, and the ‘brain-drain’ of researchers towards the USA, Mr Sørensen made the proposal to start work on a European Diabetes Research Fund. He was prepared to offer, on behalf of Novo Nordisk, a more substantial funding from the pharmaceutical industry into the proposed fund. A less bureaucratic means of managing funds for research and a means of improving the peer review process for selecting research projects were suggested to stimulate multi-national research efforts. Mr Sørensen asked: ‘If we look back in 20 years time and see that despite having the knowledge to prevent, postpone and treat the disease now, how will it appear if nothing is done?’

Mr Philippe Busquin (*Member of the European Parliament, Belgium*) said that diabetes, due to its dramatic social impact and the amount of European research in the field, belongs to the group of major diseases that Europe must consider. In order to improve the co-ordination of research efforts among the member states, the Commission launched the concept of the European Research Area (ERA), with the aim that the global research effort of the EU would reach 3% of



Lars Rebien Sørensen demonstrated how industry is rising to the challenge in diabetes research

its GDP. For its part, FP6 represents €17.5 billion for all research themes (from which only €2.255 billion goes to life sciences, genomics and biotechnology for health). Frontiers between States, lack of access to equipment and databases, diversity or lack of national research strategies, and insufficient communication between fundamental and clinical research must be overcome.

While the ERA had been created to improve co-ordination of research activities, the purpose of FP6 was to reach critical mass, to better integrate researchers, industry and academia, and to support newly created biotechnology or pharmaceutical companies.

Dr Octavi Quintana Trias then reported from the workshop ‘Strategic investment policies for diabetes research in Europe’, in which the issue of fragmentation of diabetes research and how to address it was discussed. Three levels of possible action were identified.

The first would be to set up a research agenda for diabetes, to be agreed by the scientific community and all stakeholders and implemented in several volunteering countries (ERA-NET funding scheme, next cut off date: 4 October 2005, see <http://www.cordis.lu/coordination/era-net.htm>).

The second would be the implementation of this research agenda



(corresponding call for proposals open to all scientists in the volunteering member states).

The third level would be to pool resources in a common pot for certain areas of diabetes research. The proposals made today by the industry would contribute to that goal. This third level needed a lot of courage, political will and support, but it would mean a huge breakthrough in diabetes research.

Under FP5, 22 diabetes projects had been funded amounting to €56m (of which €42m were contributed by the EU). In FP6, two calls had already been processed resulting in funding of more than €40m from the EC. The objectives of the next Framework Programme would be to further promote collaborative research, to launch European Technological Initiatives and to be more driven by researchers.

Closing remarks

Mr John Bowis (*Member of the European Parliament, UK*) concluded the conference. He said how encouraged he was, particularly by the proposal made during the conference; he thought the Parliament would be happy to 'row in' and link it to what Parliament is already pushing for – the Diabetes Framework. Mr Bowis then said how important it was for him to receive letters from constituents, people outside Parliament, to put pressure on the politicians as this was the way in which to bring issues to the attention of the budget holders and to get things done.

The EC Health and Consumer Protection Directorate General (by way of the public health action programme) had opened the door to measures to promote good health; the budget was tiny – compared to

subsidies for growing tobacco. Because of the burden it represents, diabetes was now a named disease in FP6.

In 1989 the St Vincent Declaration was agreed – 10 years on in Istanbul there had been more words than action, more targets. Now in 2004 we should ask how far we have got. We have made progress, but we have many miles to travel and there must be no weakening of our collective resolve to meet the targets for the benefit of people with diabetes.

*Report by Sarah Hills, Editor
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This conference can be heard in full in a webcast on: <http://www.easd-lectures.org/brussels>.

Diabetes nursing in Slovenia: implementation of EU and FEND guidelines

Activities of the Slovenian Society of Nurses in Endocrinology and a report of the Second Slovenian Congress of Endocrine Nursing, 21–23 October 2004, Bled, Slovenia

The Slovenian Society of Nurses in Endocrinology has organised two professional meetings each year for the past few years. These meetings are attended by members of the Society and individuals who are interested in the field of endocrinology and are involved in nursing care and health education of patients with endocrine disorders. The Society has now organised two successful Slovenian congresses with internationally recognised guest speakers.

Slovenian Society of Nurses in Endocrinology

The Slovenian Society of Nurses in Endocrinology was founded in 1988 on the initiative of Duska Vreg RN and Irena Poljsak RN. The proposal states:

'The development of medical science and technology over the past decade has brought about revolutionary changes in many fields of medicine, including endocrinology and diabetes care ... The Society intends to focus its activity on

patients who suffer from diabetes, as this is by far the most significant endocrine disorder in the world today, with grave economic and social consequences for the individual and society as a whole. Nurses are important members of the team providing care to persons with diabetes. We play an active part in strategic decisions that influence the development of diabetes care in Slovenia, and we share the responsibilities for the attainment of national goals in the field of endocrinology.'