

# PREVENTING SIGHT LOSS IN AN AGEING POPULATION



## The role of screening and early diagnosis in identifying eye diseases as comorbidities of non-communicable diseases

**European Parliament**  
**15 November 2016**

*The event was kindly hosted by  
Marian Harkin MEP and Heinz Becker MEP  
& Moderated by Ian Banks, Chair of EFAB*

**M**any eye diseases are asymptomatic in their early stages and patients are often unaware of their condition until the disease is more advanced. Eye diseases are also often a co-morbidity to non-communicable diseases, such as diabetes. All too often this vision loss is irreversible. On 15 November 2016, a panel of experts from across the eye health field gathered in the European Parliament to discuss how sight loss can be prevented through early detection of eye diseases and adequate treatment. They also presented a position paper highlighting the need to enhance screening, promote research and increase access to specialists. This document offers an overview of the interventions and the discussion.



### Welcome

**Heinz K. Becker**  
**MEP**

When it comes to health, it is up to the EU Member states to act, but the EU can make recommendations and issue guidance. The number of people affected by preventable vision impairment, most notably blindness represents an economic burden, as well as a burden to European health systems. Moreover, preventable vision impairment / blindness compromises citizens' quality of life.

I am convinced that a "shake-up" of health systems is needed. Only a mandatory system of prevention and early diagnosis, integrated in the health system as a whole, can make this happen.

The soft power of the EU should not be viewed as weak, and a strong lead from the Commission is indeed needed. We should be fighting for a lifetime of healthy ageing; from childhood onwards throughout life and with the on-going engagement of relevant actors. In Europe we already have all the necessary tools and means to put this in place.

I would like to encourage EFAB, ECV and EU EYE to submit the outputs from this meeting to me and Marian Harkin MEP, and to make us missionaries for the cause.

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## Keynote speech

**Professor Einar Stefánsson,**  
*on behalf of EU-EYE, EFAB and ECV*

Prevention is the way to deal with avoidable sight loss. Ageing and prevention are the most important matters to discuss. But first we should ask ourselves: who are we and why are we here?

We are a combined group of the people interested in this field. And we are here because we think eye diseases need more attention at the EU-level; more than 28 million Europeans are visually impaired. All eye diseases are increasing, among them: cataracts, glaucoma, diabetic retinopathy and AMD. One should however, not forget the growing incidence of myopia, which can lead to more eye diseases as well.

The WHO made the prevention of vision impairment and blindness a priority with its Global Action Plan on Eye Health, and the EU has been lagging behind in comparison. The WHO understands that in many cases, blindness is preventable and that medication is available. We would like the EU to be equally forceful.

### Our position paper highlights three key issues:

#### 1. **Research and development: much has been done in this field. There are better technologies and more effective medicines. However, there is still a lot to be done:**

- Research into novel diagnostics, medical and surgical therapies, and country-specific service models led by academia and industry.
- Eye health seems at times to be “out of sight” when it comes to publicly funded investment and research.
- It is vital that we address this, if we are to reduce vision impairment in the EU.

#### 2. **Early case finding, screening and diagnosis.**

- Early diagnosis is key to success. If you catch the patient early, the person can be treated appropriately and effectively. The same holds for diabetes. Prevention is very powerful.
- Simple, systematic and nation-wide screening and treatment is already taking place in some Member States.
- The UK is a good example of where systematic diabetic eye screening and preventive treatment has resulted in diabetes no longer being the primary cause of vision impairment and blindness in the working age population. This is however not true in most other EU countries.

#### 3. **Access to treatment and services.**

- Access to high-quality eye health care screening and services are fundamental and should be independent of geography, socio-economic status or age. This should be our mission.
- We need to build knowledge and capacity amongst primary health care workers to help people identify vision and eye health issues early and to take appropriate action, including seeking referral.
- In particular, people in high risk groups need to be systematically targeted with appropriate information and identified when they do not access services.
- The EU has taken the lead in managing the preventive approach and should consider it an opportunity to advance this.

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## In summary:

- Vision impairment is common;
- Eye diseases are rising due to ageing and the diabetes epidemic; also increase in myopia
- We need to call for a re-prioritization of policy decisions on research funding and health policy to give more priority to eye health and preventable blindness.

## Discussion



**Professor Ian Banks, Chair of EFAB** raised the question: why do individual countries do well in some cases and why is the EU as a whole lagging behind?

**Heinz Becker MEP:** The reason is that the Member States cannot find common strategies. Even if the European Parliament presents strong research findings, Member States are not necessarily incentivized to take action. We need more pressure on national governments and national policy makers. EU institutions must be strengthened and not weakened.

**Prof. Sehnaz Karadeniz:** There are many strategies, resolutions, and declarations, even in the individual Member States. However, many EU level measures are not implemented at the national level. We need to establish a pan-European network of parliamentarians.

**Dr. Grigorij Kogan:** The Treaty on the Functioning of the European Union (TFEU) leaves health policy as a competence of the Member States. There are either no obligations at all, or they are often disregarded. It would be good to bring EU and national health policies together but it is not always possible, even at the level of research because of the many differences in terms of priorities and budget.

## Expert Panel



**Prof. Sehnaz Karadeniz,**  
**President of IDF Europe**

Diabetes is one of the largest global health emergencies today. 415 million people worldwide and 32 million Europeans live with diabetes. One third of people with diabetes in Europe are undiagnosed, including 12.2 million adults. There is not one country that has diagnosed every person with the disease.

Everyone with diabetes is at risk of developing diabetic retinopathy. Diabetes can lead to many complications and could severely compromise the quality of life. If it is diagnosed early, or properly treated, these complications can be prevented.

Screening is essential for preventing sight loss. Not all people with diabetes have regular eye-checks. Prevention should be one of the key services provided.

There are various good practices, for instance in Sweden, where there have been regular screening efforts in the community of Laxå since 1983.

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There is a need for a paradigm shift, bringing about a coordinated approach with the patient at the centre. This includes the development and implementation of multi-sectoral national policies and programs, the allocation of adequate and sustained resources and surveillance and monitoring systems.

**Prof. Ian Banks,**  
**Chair of EFAB**

There is a double benefit from screening, as efforts usually help to identify other diseases like skin cancer. As a result of screenings, healthcare professional often pick up head and neck lesions.



**David Hewlett,**  
**President of FODO and the ECV**

I am delighted we are launching this position paper today. It sums up precisely all we need to do. The human population is ageing. This is a global phenomenon with massive implications and, together with climate change and access to resources, one of the three challenges facing human society in the 21<sup>st</sup> Century.

Notwithstanding devolved competences, the EU is an economic and social union and health is economics. The issues we discuss here are economic issues and health has major implications for all we are doing in the EU.

Long life is a relatively new development with massive economic and social implications. To give you an idea of these economic consequences: today, four workers sustain each retired person, but in 2060 there will only be two workers to sustain each retired person who will also be older — only half the current level of support.

Living longer is only worthwhile if it implies participation in society and quality of life.

To cope with these demographic changes, we have to promote healthy ageing and more independent living in older age as the resources will just not be available to support dependence for long periods.

To my mind preventing vision impairments and blindness is key to success here.

I welcome Heinz Becker 'spot-on' phrase "lifelong healthy ageing". With eye health we have to start early, focus on prevention and continue throughout life.

Currently the balance of investment is wrong. We invest significantly in lengthening life but nowhere near enough in quality of life issues such as eye health and preventing sensory impairment.

## **Our paper therefore highlights three key areas for action:**

1. Regular eye testing throughout life to identify disease early and prevent avoidable blindness as we age;
2. Member States making such eye care services available to everyone, irrespective of background or income;
3. Parity of research into areas such as preventing sight loss which improve the quality and well as the quantity of life.

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As professionals we also need to extend our networks and work not only with the Commission and Parliament but also with other stakeholders who are addressing these issues such as: colleagues working on active and healthy ageing, independent living and tackling health epidemics such as diabetes, to achieve these goals.



**Dr. Grigorij Kogan,**

**European Commission, DG Research & Innovation, Health Research Directorate, Non-communicable Diseases and the Challenge of Healthy Ageing Unit**

The EU support for eye health research in the FP7 comprises five pillars:

- Collaborative research, bringing together researchers from different Member States;
- Support for excellent blue sky research (European Research Council grants)
- Public-Private Partnerships, of which the Innovative Medicines Initiative (IMI) is a good example;
- Global cooperation;
- Public-Public partnerships, comprising instruments to bring together governments, patients, research institutions (Joint Programming, ERA-NETs).

The main challenge when it comes to health research is the strong fragmentation between Member States in terms of research priorities, methodologies and budgets. Another challenge is the danger of duplicating work. There is a strong need to bring together and integrate research endeavours into different international and multidisciplinary consortia.

The total FP7 budget was 54,6 billion Euro; the budget for health research was 6.1 billion Euro.

Research support for eye diseases comprised (until 2010) 62 projects, with a cumulative EU contribution of about 103,7 million Euro.

The European Vision Institute ([www.vision-research.eu](http://www.vision-research.eu)) was funded by the European Commission and the website is still active.

Horizon 2020 places emphasis on the outcome of projects and is strongly focused on:

- Jobs and growth
- Societal challenges
- European industrial leadership and competitiveness
- EU international excellence

The projects are aimed to couple research to innovation, provide an evidence-base for addressing societal challenges, support EU policies and better regulation, strengthen research capacities and innovation strategies across all Member States, multi-disciplinarily and synergies, and to address people's concerns.

In Horizon 2020 Health Research is recognised as a key societal challenge and has Euros 29 billion funding. Of this, eye research has 24 projects with Euros 46 million funding.

Mr Kogan highlighted the Eye Risk project on AMD which has Euros 6m funding and is coordinated by the University of Tübingen. He highlighted that prevention accounts for only 3% of healthcare spending. But if one could be more efficient in this area then budgets for treatment would be lower.

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Mr Kogan also highlighted the IMI 2 topic on Dry Age Related Macular Degeneration launched within the 7<sup>th</sup> Call in December 2015. The project funded in this call may receive Euros 8 m funding each from EFPIA and from the Commission. The second stage of the proposal submission had a deadline of September 6, 2016 and the proposals are currently being evaluated.

## Discussion

The interventions were followed by an interactive discussion between the panellists and the audience. What follows highlights the main contributions.

**Prof. Carlo Traverso** – We are all unhappy with the existing top-down approach and we thus need to move to a bottom up approach, starting with the stakeholders making more noise. The Commission is aware of the importance of prevention and has invested time and money in raising awareness, but now we need a bottom up approach.

**Prof. Ian Banks, Chair of EFAB** – but how do we make this happen? Who should initiate this? Action is needed, more than awareness raising.

**Peter Gumpelmayer, ECOO** – a combination of both: a bottom-up and a top-down approach is needed. For the bottom-up approach we should involve our national members and we could start with a simple meet and greet and take it from there.

**Johannes Trimmel, IAPB** – we have proven that the impact can be increased by working together but it does not seem to be enough. It would help to have a broader strategy that starts at the national level and is supported at EU level.

**Dr Grigorij Kogan** – the bottom up approach is already implemented in the calls of the Horizon2020 programme.

**Prof. Sehnaz Karadeniz** – at IDF Europe we have started to reach out to and communicate more with our Member associations and make the change from the ground.

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## Closing Remarks

*Marian Harkin,*  
*MEP*

In this room, we all know what the problem is; we have discussed the impact of diabetes, and noted that there are many people who do not believe that 50% of blindness is preventable. We are also all open to the idea of a bottom-up approach combined with a top-down approach.

The reason why action at EU level is lagging behind is due to the lack of EU competence in the field of health and the lack of power to act. Member States lead, while the EU institutions support the Member States.

But this is just a piece of a bigger jigsaw puzzle. Perhaps the answer is in getting something in the European Council Conclusions. This would imply another push forward, especially because it means that the issue has landed on the agenda of the EU Member States.

My office would be willing to offer support or even get information to share.

It is time to move on. Even though it is good to get together with like-minded people, we need to move on to action with people who know how the systems work.

Much can be done at the EU level, but even more so at the level of the Member States. The Council conclusions would be a good way forward.

It is great to be involved and please keep knocking on our door.

