



Retina
International



Manifesto

Retina Action - Act to make AMD – the leading cause for vision loss in Europe a European Public Health Priority

1. Introduction

Age-related macular degeneration (AMD) is a serious eye disease that is the leading cause of blindness in people over the age of 50. In Europe alone, almost 1 in 10 (60.75m) people live with a form of AMD, early, intermediate or late stage. Of these, 7% (4.43 million) have the most severe and blinding late stage of the disease, which includes neovascular AMD (nAMD) and geographic atrophy (GA). (1) The prevalence of AMD is on the rise. In the last 10 years, the number of people living with AMD in Europe has grown by more than 10% from 55 million to 60.75 million, equivalent to the population of Italy. By the year 2040, it is estimated that more than 1 in 8 (69.32m) will be affected by the disease. (1)

AMD causes the gradual loss of central vision, which can impair people's ability to perform daily activities, such as reading, watching TV, cooking, driving, and recognising faces. AMD can also have a negative impact on the mental health and well-being of those affected and their caregivers. Studies have shown that up to 44% of people living with AMD experience anxiety and depression. (2)

I was 63 when I was diagnosed with AMD. It took me years to recover from this blow. Accepting the decline of vision, and the loss of autonomy that comes with it, is not easy. As a grandmother, the fact that I can no longer recognise the faces of loved ones is one of the hardest parts."

Ginette G, 78, Paris, France

Additionally, late-stage AMD imposes a significant economic burden on individuals and society. A recent study conducted by Retina International in Bulgaria and Germany estimated the total annual cost of late-stage AMD to be 449 million and 7.6 billion Euro, respectively. (3) Despite the high and increasing prevalence of AMD and its growing economic impact, the EU has not yet developed a comprehensive framework or strategy to address eye care and prevent blindness among its citizens.

In line with the Sustainable Development Goals 2030, the World Health Organisation (WHO) and the United Nations (UN) have provided strategic recommendations and resolutions to promote vision for everyone (4,5). These recommendations could serve as the basis for a comprehensive framework for eye care in Europe which, in turn, could facilitate the creation of national plans and strategies on eye care across Member States (MS). The development of such a policy framework would represent a crucial step towards ensuring that eye care becomes a public health priority in Europe, curbing the rising tide of vision loss, particularly in the aging population.

As a global umbrella organisation of 43 patient-led voluntary groups, charities and foundations, whose common goal is the preservation and restoration of vision, Retina International is concerned that the AMD community has a significant unmet medical need and that their views and experiences are not adequately represented in the development of relevant health policies within the EU.

To address this gap, Retina International has formed the Retina Action Coalition with its European members and developed and adopted this Manifesto, which is informed by scientific research and the real-world experiences of people affected by AMD.

The purpose of this Manifesto is to guide the political programmes of the candidates for the European Parliament, the future European Commission, and the development of all policies that affect people living with AMD and their caregivers in Europe.

2. A Call for Action: Retina International's Key Policy Asks

With this Manifesto, Retina International and its European member organisations call on the European Parliament to prioritise the development and provision of appropriate eye care strategies for all European citizens, especially for the millions living with AMD.

In the medium term, we call for the development and implementation of a comprehensive European policy framework making eye care a public health priority across Europe and stemming the rising tide of AMD-related vision loss.

In the short term, we call on incoming MEPs and political parties and groupings to take immediate action in the following three priority areas:

1. Early detection and access to treatments and rehabilitation services
2. Research and innovation
3. Mental health

1. Enable early detection and access to treatments and rehabilitation services (medical devices and assistive aids)

The prevalence rates for AMD among the working population aged 50–59 years in Europe is growing. The steep rise in the number of those affected coupled with the increasing age of retirement means the negative impact of AMD on economic activity is becoming increasingly pronounced.

Early detection is essential for timely diagnosis and optimal care for people living with AMD. Those with the early and intermediate stages of AMD do not usually experience obvious symptoms. Therefore, without early detection programmes, diagnosis can come too late for treatments and/or lifestyle changes to be effective.

“In Germany, there are no funds for rehabilitation programs for senior citizens e.g. learning practical life skills, introduction to orientation and mobility and use of technical devices such as smart devices, using the internet and screen readers and useful apps. Funding of barrier-free accessibility to digital devices, funds for inclusion in public and cultural life is needed.”

Ulrike Gerstein, 79, Hamburg, Germany

Differences in early detection capabilities and adoption of new technologies across Member States create inequalities for patients. In addition, aging people living with AMD often have comorbidities and must go through long, complex, and fragmented care pathways.

It is also a major challenge for people living with AMD to obtain adequate disability assessments in their Member States leading to exclusion from access to social care, services and independent living.

Medical devices and assistive aids are critical to enhance the quality of life for AMD patients, however, they may not be included in a reimbursement system or available through a dedicated programme in all Member States. (6)

We welcome proposed changes to existing legislation designed to strengthen incentives for the faster launch and earlier access to medicines for patients and call on Member States to meet their responsibility of ensuring their availability, access and affordability as part of their responsibility to provide effective universal

health coverage. This can be achieved through strategies for expanding early access programmes; ensuring legal clarity for cross-border access to approved treatments; and reviewing the directive on pricing transparency for medicinal products under national health insurance systems.

To ensure the early detection and timely access to treatment and rehabilitation services, including medical devices and assistive aids, Retina International calls on incoming MEPs and political parties and groupings to:

- Acknowledge AMD patients as a vulnerable population with a high unmet need and to establish a comprehensive European approach to the early detection of AMD through the creation of a European multistakeholder expert group.
- Design and implement early detection programmes through enhancing the collaboration across Member States. This will ensure the identification and sharing of best practices and the equitable implementation of advanced diagnostic technologies.
- Guide the establishment of available, accessible, affordable, and standardised rehabilitation services for individuals with AMD that address their mobility needs and bridge digital inequalities. This should be achieved through the implementation of standards for low vision rehabilitation in Member States; collaboration for sharing of best practices; and the consistent implementation of national programmes.
- Direct Member States and their regions to approve national protocols for social and healthcare coordination of eye care as a guide for patients and carers on access to services, benefits, and aids. To support this, best practice examples of peer-to-peer support should be identified and shared across Member States, and their implementation funded through national or European programmes.

Retina International recommends a stepwise approach to introduction of early detection programmes for AMD:

- In countries where there are routine early detection services for Diabetes Related Eye Diseases (DED), we call for the addition of AMD screening.
- Early detection services for AMD in the over-50s (independent of the presence of diabetes) will best be achieved by subdividing this group into low/medium/high risk groups, based on family history, age, genetics, and other appropriate risk factors, and introducing screening in a stepwise manner.

2. Prioritise research and innovation for AMD, including basic, translational, social, and patient-centric research

The understanding of how AMD develops requires ongoing research due to its complex pathology, including genetic and environmental risk factors; exploration of new biological pathways and molecular targets; and the development of novel treatment modalities, such as gene therapies, stem cell therapies, and advanced drug delivery systems. To support this research, bottom-up funding mechanisms like those provided by the European Research Council and Horizon Europe are essential.

“We have already had treatments that slow wet macular degeneration for almost 20 years, and we are eagerly awaiting a treatment to slow or treat dry macular degeneration. We all know that recent therapies exist in the United States and Japan, and we hope that we can also be treated quickly in Europe and France.”

Ginette G, 78, Paris, France

Despite considerable advances in the understanding of the neovascular form of AMD, the complete understanding of the mechanisms of Geographic Atrophy (advanced form of dry AMD) remains a future prospect. Consequently, Geographic

Atrophy remains without a therapeutic option in Europe; a fact that further highlights the urgent need for both basic and translational research.

Studies to understand the patient perspective of the disease – including socio-economic studies, patient preference studies and the impact on caregivers – must be prioritised to ensure better therapeutic outcomes for the affected population.

To ensure the much-needed prioritisation of research and innovation for AMD, including basic, translational, social, and patient-centric research, Retina International calls on incoming MEPs and political parties and groupings to:

- Continue to promote cross-border and cross-sectoral collaboration on AMD research, particularly under the Horizon Europe programme, and to invest in infrastructures that advance research led by patients' needs.
- Optimise the use of resources through strategic investments and the incentivisation of all stages of research to achieve excellence in basic, translational, social, and patient-centric research; and to develop and fund a robust European science agenda with particular attention to the specificities of AMD.
- Promote and facilitate patient engagement in AMD research, and to make Europe a leader in patient involvement.
- Enhance long-term multinational public-private research partnerships and to spearhead international research collaboration through international consortiums.

Retina International welcomes the long-awaited revision of the EU pharmaceutical legislation. This is a once-in-a-generation opportunity to make the EU regulatory framework more person-centred by promoting patient involvement in the regulatory process; improving access to and availability of medicines; and developing new treatments to better address unmet patient needs.

The definition of ‘unmet medical need’ should be created in cooperation with patients and include criteria important to them, such as quality of life.

3. Address the mental health needs of people living with AMD and their caregivers by developing actionable national and regional initiatives.

The mental health and well-being of those who live with AMD can be significantly impacted by the disease. Studies indicate that nearly half of those affected by AMD suffer from anxiety or depression. (2)

Retina International welcomes the European Commission initiative to develop a long-term, comprehensive and integrated European strategy on mental health. As part of this, we believe that the Commission and EU Member States should guarantee attention is given to the psychological and emotional aspects of people living with AMD and for their caregivers, to enable acceptance and guide the patients after the diagnosis.

Support should be provided in cooperation with national civil society organisations and funded through the European and national budgets available for psychological and mental well-being. On a regional level, this would allow AMD-specialised centres or organisations to enlist the assistance of mental health professionals to support and guide AMD patients and caregivers.

To ensure the development of actionable national and regional initiatives that address the mental health needs of people living with AMD and their caregivers, Retina International calls on incoming MEPs and political parties and groupings to:

“I had to give up playing the piano, which was very important and nourishing for me, especially playing chamber music in the group, because I could not read the sheet music anymore. My independence was shaken. I had to abandon driving the car. I could not participate in special educational programs outside of town or attend festivals. This really frightened me a lot. And I asked myself: “How can I manage my daily life in the future?” I used to be an independent woman and suddenly I was dependent on others. My freedom of movement was limited, e.g. to handle technical devices in the house and garden and in public life. AMD happens when you are getting older anyway and then the vision loss comes on top. You must adapt and learn to do things in a different way, that you were used to do all your life. Fortunately, the vision loss progresses slowly, so that I was able to get used to it, but it is a hard job. Today, I am legally blind.”

- Ulrike Gerstein, 79, Hamburg, Germany

- Identify, share and promote best practices that improve the mental health and psychosocial wellbeing of aging people with AMD and their caregivers.
- Direct national governments to develop corresponding national mental health strategies with clear timetables, adequate budgets, concrete targets and KPIs to monitor progress.
- Develop and implement prevention initiatives within and across policies that address the needs of aging people with AMD and their caregivers, including initiatives against depression, anxiety and suicide, as well as initiatives that prevent and mitigate loneliness and social isolation.
- Improve the quality and accessibility (waiting times, travelling distance and affordability) of mental health services and care for aging people with AMD.

3. Conclusion

The detailed policy recommendations set out in our Manifesto focus on three key areas that were identified by Retina International's patient-led member organisations as urgent priorities. We believe that appropriate policy responses to these three areas would represent an important first step towards the development of a robust framework for eye care in Europe. This would elevate eye care to a European public health priority, ultimately ensuring the provision of adequate eye care for all citizens of the European Union.

The Retina Action Coalition has developed and adopted this Manifesto to guide the political programmes of EU policymakers. With their support, we can work together to stem the rising tide of AMD and build a healthier, inclusive and more prosperous future that everyone can see.

References:

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