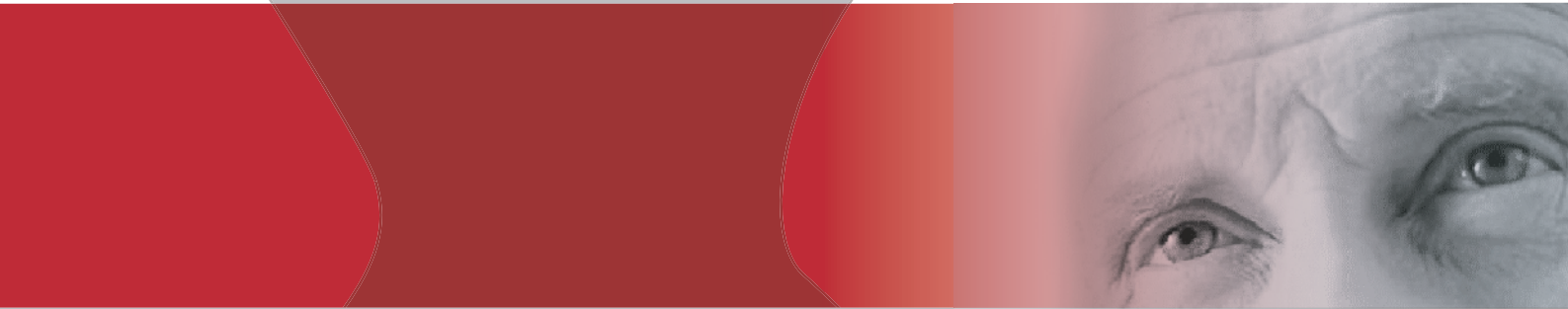


# Awareness of Age-related Macular Degeneration and Associated Risk Factors



AMD Global  
Report 2005



"I used to smoke up to 60 cigarettes a day. Now I have wet AMD, am partially sighted in one eye and am likely to lose my sight. When you smoke you cannot imagine what it is like to have lung cancer and especially when you are young the risk of dying earlier doesn't come into it. I am a nurse, I saw people die from smoking-related diseases and that did not make me kick the habit. But if I had been told that I could lose my sight because of smoking I am sure I would have given up earlier. I stopped the day I found out."

Pauline M. Edwards  
UK, aged 50

"We have made considerable progress in identifying the risk factors linked with AMD in the past few years. While smoking remains the main modifiable risk factor, growing evidence suggests that many of the aspects that we associate with a healthy lifestyle – a balanced diet, exercise, low cholesterol levels, etc. – also help to keep our eyes healthy. We cannot (and would not want to) escape the fact that we grow older but we can try to minimize the risk of developing AMD by taking preventative measures."

Dr. Johanna Seddon, Director, Epidemiology Unit,  
Massachusetts Eye and Ear Infirmary, Boston, USA  
and Member of the Scientific Advisory Panel  
of the AMD Alliance International

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# AMD Alliance International: Global Report 2005 Awareness of Age-related Macular Degeneration and Associated Risk Factors



## *Table of Contents*

<b>Summary of Main Findings and Call for Action</b> .....	4
<b>Section 1: General Awareness of AMD</b> .....	6
<b>Section 2: Risk Factors and Prevention</b> .....	9
2 (a) Unavoidable or non-modifiable risk factors ....	10
2 (b) Avoidable or modifiable risk factors .....	13
2 (c) Recommendations for preventative actions ....	15
2 (d) Measuring global awareness of risk factors ....	16
<b>Section 3: Call for Action</b> .....	19
<b>References</b> .....	21
<b>Annex</b> .....	24
Annex 1: About AMD Alliance International .....	24
<b>Useful Addresses and Links</b> .....	24

## Summary of Main Findings and Call for Action

According to the World Health Organization age-related macular degeneration (AMD) is the leading cause of blindness in developed countries [1]. Despite this a survey carried out by EOS Gallup Europe on behalf of the AMD Alliance International in March 2005 shows that awareness of AMD is alarmingly low. The highest awareness levels were measured in the United States (30 per cent), Canada (25 per cent) and Australia (21 per cent). The United Kingdom (16 per cent), South Africa and Germany (14 per cent), France (13 per cent), Ireland (11 per cent) and Switzerland (10 per cent) occupy the middle ground, whereas in Spain, the Netherlands, Hong Kong, Italy and Japan less than one in ten respondents are aware of the condition.

Equally worrisome is the fact that even those familiar with the condition have little appreciation of the factors that increase the risk of developing AMD. This is particularly true for the only scientifically proven modifiable risk factor: smoking. Whereas 62 per cent of respondents who were aware of AMD named age as a risk factor and 44 per cent thought that a family history of the condition increased the risk, only 32 per cent were aware of the causal link between smoking and AMD. Unprotected exposure to sunlight was equally named by 32 per cent of respondents whereas 36 per cent named lack of vitamins and nutrients.

In terms of prevention, raising awareness of the link between smoking and visual impairment is an essential first step to behavioural change. However, in the majority of countries surveyed (eight out of 14) less than 50 per cent of all respondents thought that smoking could harm their sight. Australia stands as a notable exception with 77 per cent of respondents identifying smoking as harmful to vision. We believe this to be a direct outcome of the government funded nationwide advertising campaign about the link between smoking and blindness.



## The Consequences of Inaction!

It is an established fact that the global number of people who will lose their sight because of AMD will increase, if only because of our aging population. The costs of vision loss, both to individuals and their families and to society, are therefore likely to increase. For Australia alone (population 20 million) the overall costs of blindness in 2004 were estimated at \$9.85 billion. Given that AMD is the leading cause of vision loss in developed countries, a significant part of these costs is likely to be attributable to AMD. Prevention, early detection and treatment are keys to reducing these costs.

## Urgent Action Needed Now!

Increased awareness of AMD is essential. Increased awareness of AMD will allow individuals to make informed lifestyle choices (particularly in relation to smoking) to reduce the risk of vision loss from AMD. We must educate the general public and health care professionals about the modifiable factors that increase the risk of developing AMD, but the AMD Alliance and its members cannot do this alone. We state firmly to our governments – **preventing blindness and helping visually impaired people lead independent lives is a moral imperative that makes strong economic sense**. Immediate action is required: Partner with us now to ensure that AMD does not remain the unknown cause – and cost – of blindness and severe vision loss.

On behalf of AMD Alliance International

**Gerrard Grace**  
Chairman  
AMD Alliance International

**Steve Winyard**  
RNIB  
Vice-Chairman  
AMD Alliance International

## Section 1: General Awareness of AMD

AMD is a degenerative retinal eye disease that causes progressive loss of central vision. AMD affects the macula – the central part of the retina – responsible for clear, central vision needed for daily activities such as reading, driving or watching TV. As light-sensing cells in the macula, called photoreceptors, begin to deteriorate, so does the individual’s central vision. It usually starts in one eye and is highly likely to affect the other eye at a later stage. Common symptoms are blurred or distorted vision but there are often no signs of vision loss in the early stages. We distinguish between two types of AMD. Dry AMD is the most common form of the condition and develops slowly, eventually leading to a loss of central vision. Currently, there are no treatments for dry AMD. Leaking blood vessels inside the eye cause wet AMD. It is less common (10 to 15 per cent of the total) than dry AMD but it can cause more rapid vision loss. If detected in time, treatments for some forms of wet AMD are effective in reducing or delaying sight loss. The extent of vision loss varies widely and is related to the type of AMD, its severity and other individual characteristics. While individuals with AMD usually retain some residual vision, vision loss can be so severe that it is classed as “legal blindness” in most countries.

In 2005 the AMD Alliance International commissioned EOS Gallup Europe to conduct a global survey to assess awareness of AMD and the risk factors associated with the disease. A total of 15,048 people were interviewed in 14 countries: Australia, Canada, France, Germany, Hong Kong, Ireland, Italy, Japan, the Netherlands, South Africa, Spain, Switzerland, the UK and the United States of America.

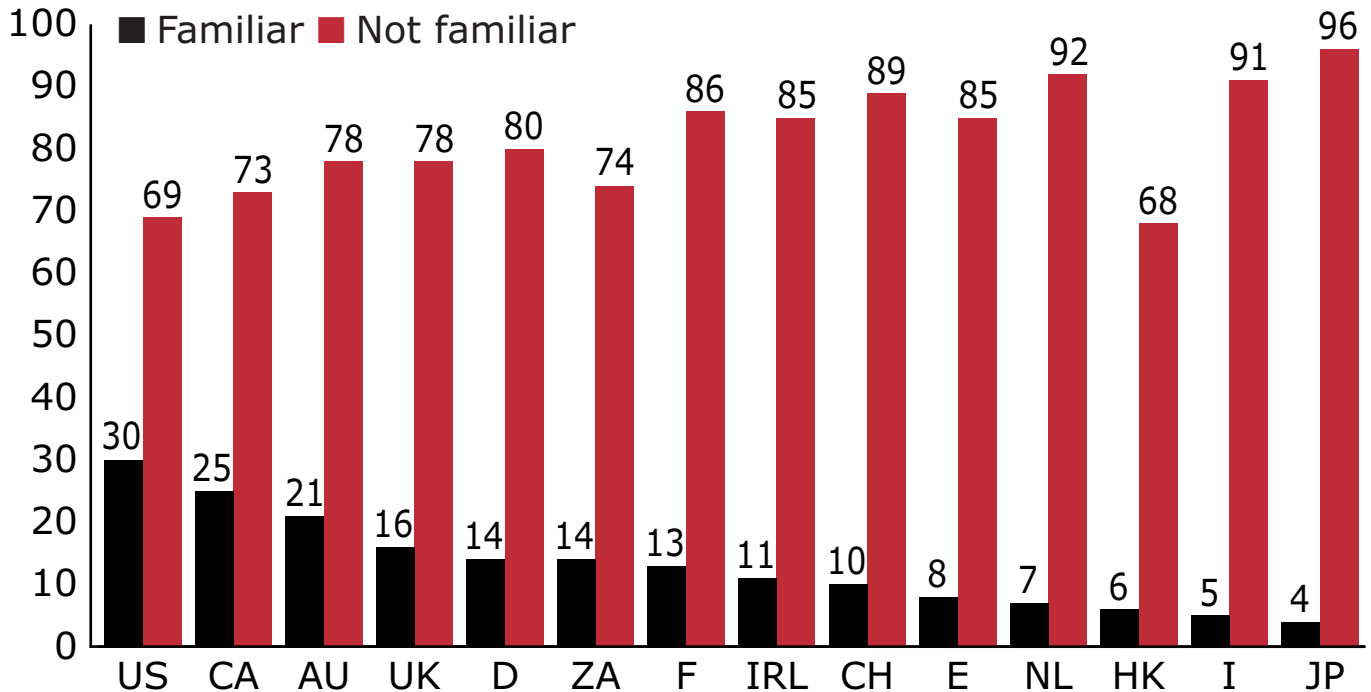
The question used to establish awareness levels was:

“How familiar are you with the medical condition known as age-related macular degeneration or AMD?”

- a) Very familiar .....1
- b) Somewhat familiar.....2
- c) Not too familiar .....3
- d) Not at all familiar .....4
- e) [DK/NA] .....5



**Figure 1. Awareness of AMD**



US: United States of America, CA: Canada, AU: Australia  
 UK: United Kingdom, D: Germany, ZA: South Africa  
 F: France, IRL: Republic of Ireland, CH: Switzerland, E: Spain  
 NL: Netherlands, HK: Hong Kong, I: Italy, JP: Japan

The results show highest awareness levels in the USA, Canada and Australia with 30 per cent, 25 per cent and 21 per cent of respondents respectively stating that they are very familiar or somewhat familiar with AMD. The UK (16 per cent), South Africa and Germany (14 per cent), France (13 per cent), Ireland (11 per cent) and Switzerland (10 per cent) occupy the middle ground, whereas in Spain, the Netherlands, Hong Kong, Italy and Japan less than one in ten respondents was aware of the condition.

Because individuals will have different views of what it means to be "somewhat" or "very familiar" with a condition, we used a control question, asking all respondents whether they were familiar with AMD or not, what body part they thought was affected by the condition. Respondents were able to choose from a list of organs including the eyes.

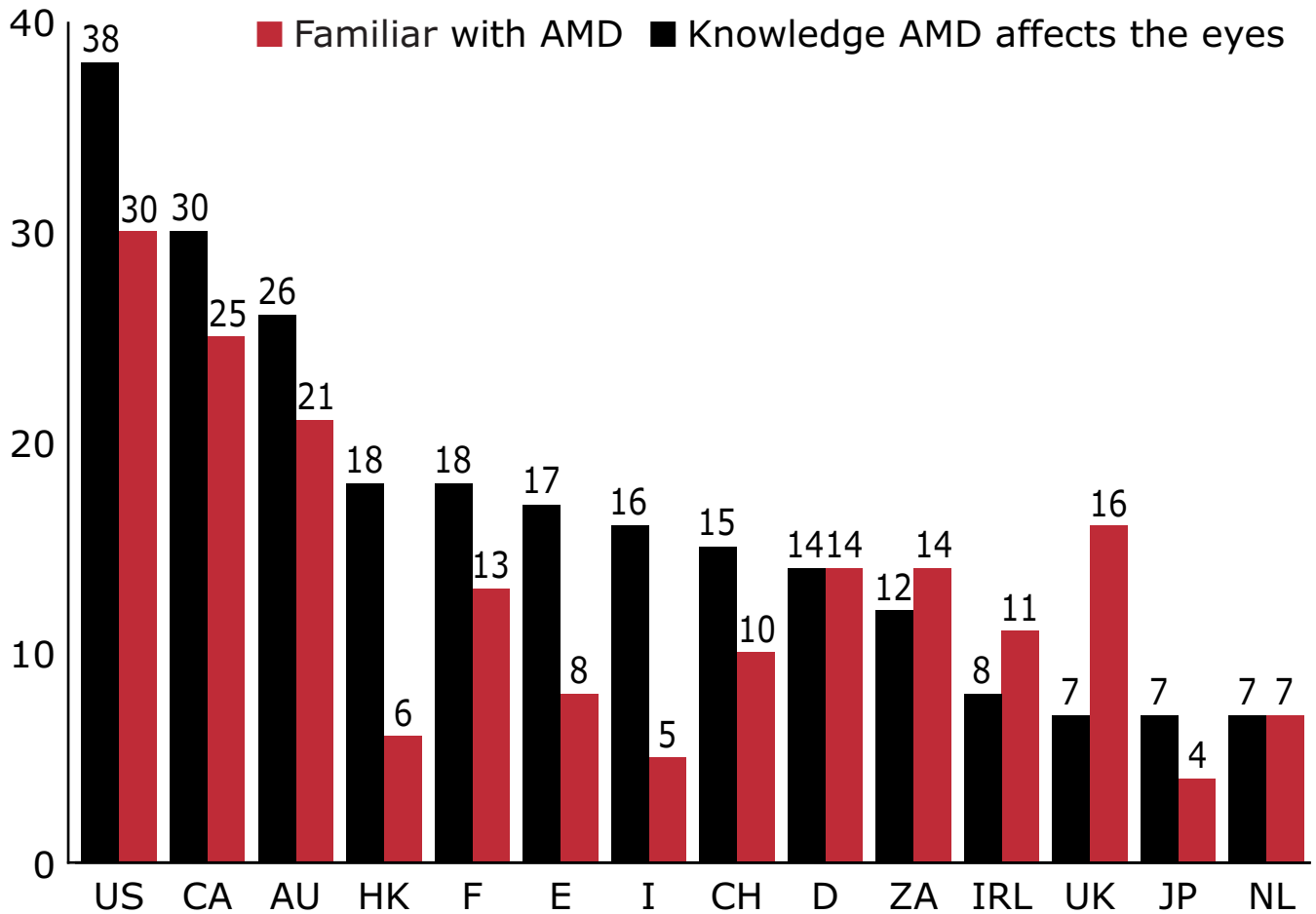
Interestingly, the responses to this question show that, in the majority of countries, the percentage of people correctly linking AMD with the eyes is greater than the percentage of people stating that they are familiar with AMD (see figure 2 below). In these countries (particularly Hong Kong, Italy and Spain) the control question shows that a significant number of respondents may have felt uncomfortable stating that they were familiar with AMD, even though they had heard of the condition and were able to identify the affected body part. This would confirm our own assessment that awareness “on the ground” is in fact higher than suggested by the low general awareness figures for these countries.

At the same time the results show that we cannot assume that all those who said that they were familiar with age-related macular degeneration did so on the basis of factual knowledge. In some countries (UK, Ireland and South Africa) respondents clearly overstated their knowledge of the condition since the percentage of people claiming familiarity with AMD was higher than the percentage of people linking AMD with the eyes. This raises the challenge of ensuring that awareness campaigns are successful in going beyond the “have you heard of” aspect of familiarity and generate awareness linked with factual knowledge and action.

Perhaps more importantly, we know that globally there is much less awareness of AMD than any other common eye condition, despite its growing prevalence. Surveys have shown awareness of cataracts to be as high as 95 per cent in Spain and the UK [2]. Given increased knowledge about prevention and increasing availability of treatments this is the level of awareness we should aim for with age-related macular degeneration.



**Figure 2. Awareness of AMD v. Knowledge of affected body part**



US: United States of America, CA: Canada, AU: Australia  
 HK: Hong Kong, F: France, E: Spain, I: Italy, CH: Switzerland  
 D: Germany, ZA: South Africa, IRL: Republic of Ireland  
 UK: United Kingdom, JP: Japan, NL: Netherlands

## Section 2: Risk Factors and Prevention

The survey results discussed above illustrate how difficult it is to raise general awareness of AMD, yet this is the prerequisite for any work on prevention. If people are unaware of a condition that may affect them in later life, they are unable to take targeted preventative action.

Before we discuss the results of our survey questions on risk factors, we would like to present the current understanding of factors that increase the risk of developing AMD and recommendations for preventative measures.



## 2 (a) Unavoidable or non-modifiable risk factors

So why should we be aware of the unavoidable risk factors of AMD? Some people may think that there is not much point knowing of a higher risk if you cannot do anything about it.

We feel that it is important to take a more positive, proactive approach. People need to know if they are at a higher risk of developing AMD so they can focus on avoiding the environmental risk factors that could increase this risk even further. They also need to be made aware of their increased risk to ensure that they take early detection particularly seriously. The recommendation from the AMD Alliance's Scientific Advisory Board is that people aged 55 or older should have regular eye examinations every two years. This should consist of a dilated fundus examination performed by a qualified eye health professional. However, people who experience loss of vision or distorted vision should immediately consult a qualified eye health professional and should follow his or her advice regarding follow up. By following this advice people who develop AMD increase their chances of accessing the growing number of treatment options and rehabilitation services available in most countries.

The unavoidable factors that increase the risk of developing AMD discussed below are:

- Aging
- Family History/Genetics
- Gender
- Ocular factors such as hyperopia and lower disc/cup ratio
- Ethnic group and iris colour

Aging and family history or genetics are unavoidable risk factors whose link with AMD is firmly established.

### Aging

As the name of the condition suggests, age-related macular degeneration is a condition that is clearly linked to the aging process. Even though figures on the prevalence of AMD vary greatly depending on the definition used, it is clear that the likelihood of developing the condition increases considerably with age. Prevalence increases



from 12.2 per cent in people aged 55–64 years to 18.3 per cent in those aged 65–74 years and 29.7 per cent in people aged over 74. It is important to note that not all of these will be cases of advanced AMD resulting in vision loss. In fact the figure for those with advanced AMD above the age of 75 is 7.8 per cent [3].

Because of this age profile, the vision loss associated with AMD was for a long time considered to be an inevitable consequence of aging. Even today, when there is treatment available to halt the progression of the most aggressive form of the disease and low vision rehabilitation helps many patients to continue autonomous lives, many people still believe that they just have to “put up” with their deteriorating sight rather than exploring treatment and low vision rehabilitation options.

## **Family History/Genetics**

Studies of twins and evidence that first-degree relatives of people with AMD are more likely to develop the condition themselves, suggest that genetic predisposition is one of the risk factors for AMD. However, it is only in the past five years that significant progress has been made in identifying the genes that are involved in the disease process. Four research papers published in 2005 [4;5;6;7] now report identifying a gene on chromosome 1 which is responsible for the production of the so-called “complement factor H” (or CFH) protein. In people with AMD changes to the DNA lead to a change in the sequence of amino acids that form this protein. The CFH protein is involved in the control of inflammatory processes. Scientists therefore believe that the variant protein may be associated with inflammation within the retina. However, more research is required to define more accurately the role of the abnormal CFH protein in the development of AMD. Current data suggests that people who have inherited the variant CFH gene from one parent have a two to four times increased risk of developing AMD. If both parents carry the variant CFH gene the increased risk is five- to seven-fold. Putting it another way, the current data suggests that the change to the sequence of the CFH protein possibly accounts for 20–50 per cent of the overall risk of developing AMD. These findings are significant because people, and in particular those with a family history, may be able to undergo screening for the variant CFH gene to assess their risk of developing AMD well before they develop any symptoms. More importantly, powerful technologies



are being developed to manipulate the process that transforms genetic information into proteins. This means that it may be possible to suppress the “misinformation” contained on the variant CFH gene to avoid the increased risk of developing AMD. (For a more detailed discussion of the role of genetics in the development of AMD, written by Prof. Peter Humphries, member of the AMD Alliance International Scientific Advisory Board, please go to: [www.amdalliance.org](http://www.amdalliance.org).)

Other unavoidable risk factors have been linked to AMD but some of the evidence is not consistent:

### **Gender**

It is a common assumption that women are more likely to develop AMD. However, the evidence is not strong since the larger number of women with AMD may simply be a reflection of their greater longevity. Generally, there does not seem a significantly increased risk for women as compared to men [8]. It is also worth noting that a study in Japan has found the prevalence of AMD to be higher in men than in women [9].

### **Ocular factors such as hyperopia and lower cup/disk ratio**

AMD has been linked to hyperopia (farsightedness) [10] and a lower cup/disc ratio [11]. People with these conditions should be made aware of the importance of regular eye tests and should be encouraged to test their vision with the Amsler Grid. This is a wise precaution even though the impact of these factors has not been quantified, and not all studies have evaluated these parameters.

### **Ethnic group and iris colour**

It is generally accepted that Caucasians are more likely than others to develop AMD, even though some studies have suggested similar or even higher prevalence rates for African and Asian populations [12;13;14]. In addition, people with blue or hazel eye colour [15] appear to have a higher risk and Caucasians with AMD seem to be more likely to progress to the advanced stages of AMD [16]. One of the problems with current prevalence figures is the lack of a universally accepted definition of AMD, which means that it is difficult to compare different studies. It should also be noted that in Asia and Africa a more common form of age-related macular degeneration is polypoidal choroidal



vasculopathy (PCV), which is not yet well understood and for which accurate prevalence figures are even harder to find. This explains the difficulty of establishing to what extent ethnic groups differ in their susceptibility to AMD.

## 2 (b) Avoidable or modifiable risk factors

Avoidable risk factors are those that are open to behavioural modifications, or in other words are environmental factors that individuals can control.

The following modifiable risk factors are discussed below:

- Smoking
- Lack of nutrients and antioxidants
- Obesity, high blood pressure, fat intake and cholesterol levels
- Light exposure

### Smoking

The only avoidable risk factor that can be regarded as proven is the link between AMD and smoking [17]. The first prospective study in 1996 definitively demonstrated an association between AMD and smoking [18]. The most recent study on smoking and AMD was published in the *British Journal of Ophthalmology* on April 14, 2005. A study of more than 4,000 Britons aged 75 and older showed that those who smoke were twice as likely to have age-related macular degeneration as those who did not [19]. Other studies have come to the conclusion that the risk may be as high as three to four times that of a non-smoker [20;21]. In addition, a review of the association between smoking and age-related macular degeneration that examined the results of 17 studies into the link has found that scientific evidence is sufficiently strong to prove that smoking causes age-related macular degeneration. The causality criteria used were the same as those applied to proving the link between smoking and lung cancer [22].

Studies in a number of countries confirm that people who stopped smoking 20 years before have a similar risk of developing AMD as non-smokers and the risk starts to decrease after 10 years of not smoking. Some studies also suggest that there is a link between the number of packs smoked and the likelihood of developing AMD [23].

There is now sufficient evidence to show that smoking is the main modifiable risk factor for developing AMD. It is responsible for at least a two-fold increase in relative risk, while some studies suggest the risk could be as high as three- to four-fold.

### **Relatively low levels of micronutrients and antioxidants**

The best known food supplement for AMD, the so-called AREDS formula, is recommended only for people with intermediate or advanced AMD [24;25;26]. Anybody considering taking the AREDS formula as a supplement should discuss this with their eye care professional. They should be aware of concerns about the link between beta-carotene and cancer in smokers. They also need to realize the danger of oversupplementation if they use other supplements in addition to the AREDS formula. Of course, primary care doctors should be informed in case there is interaction with other medications.

The main supplements discussed in the context of prevention are lutein and zeaxanthin. Lutein and zeaxanthin are two antioxidants that are concentrated in the macula and constitute the macular pigment [27]. It has been suggested that they may play a significant role in preventing oxidative damage to the macula, thereby preventing the development of AMD. What is particularly significant is the fact that some studies have shown lutein to improve some measures of visual function [28;29]. However, samples studied were small and further studies are required to come to a firm conclusion on the benefits of both antioxidants and decide whether this food supplementation is to be generally recommended as a preventative measure.

### **Obesity, high blood pressure, fat intake and cholesterol levels**

Age-related macular degeneration has also been linked with obesity [30;31] and high blood pressure (hypertension), particularly in people taking antihypertensive drugs [32]. In addition, a high intake of dietary fats (especially saturated and monounsaturated) was linked to a higher risk of developing AMD [33] and of progressing from the early and intermediate stages to the late stages of the condition [34], whereas omega-3 fatty acids and fish tended to reduce risk [33,34]. In addition, AMD has been linked with high cholesterol levels but again the evidence is not conclusive [35;36].



## Light exposure

Ultraviolet light probably does not harm the macula since it does not reach it. However, there is some evidence that blue or visible light (400–700 nm wavelength) may be associated with a higher risk of developing AMD [37]. The Beaver Dam Eye study [38] showed an increased incidence of AMD in people who spent long periods in the summer sun but no significant link with exposure to environmental light in general. On the other hand McCarty et al. [39] did not find any link between light exposure and AMD.

## 2 (c) Recommendations for preventative actions

Many of the preventative actions that people can take to decrease the risk of developing AMD are part of an overall focus on a healthy lifestyle. These include:

- Eating a diet low in fat but rich in vegetables (especially green leafy vegetables), nuts and fish.
- Controlling body weight, blood pressure and cholesterol levels.
- Wearing sunglasses at midday to protect your eyes as part of a general eye health routine.

People should also check their family history in relation to eye disease. Those who have first-degree relatives with AMD should see their eye care professional and have a fundus examination. If they are found to have intermediate AMD, or advanced AMD in one eye, then they should take the AREDS type supplement and adhere to healthy habits.

However, the strongest and most important message regarding prevention of AMD is **do not smoke, and if you do, stop!**

Since smoking is the one proven modifiable risk factor for developing AMD, people need to be encouraged to stop. This is often easier said than done and it is therefore important to encourage people to seek help from qualified professionals. In most countries governments and voluntary organizations run programs to help people quit.

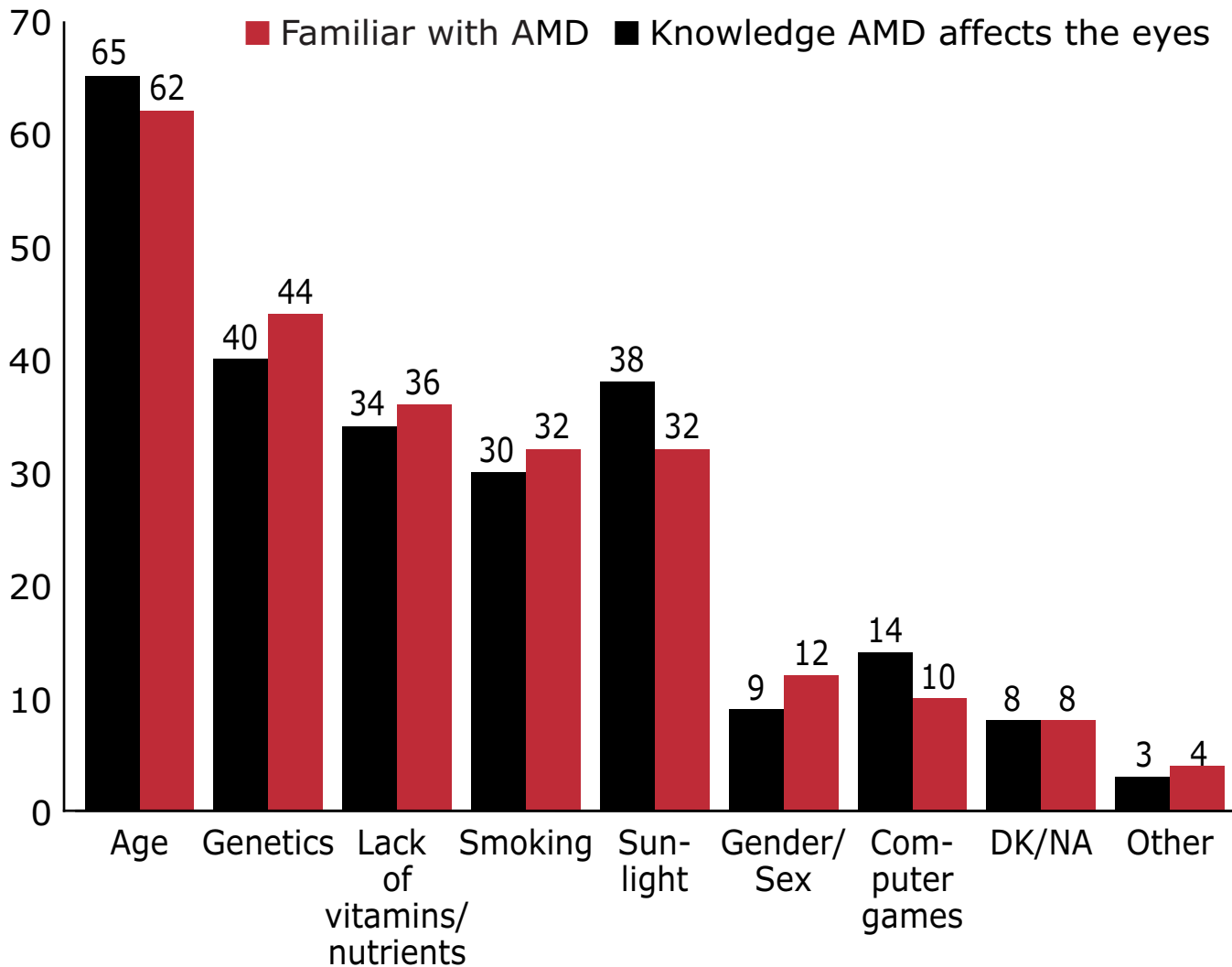
## 2 (d) Measuring global awareness of risk factors

In line with this report's topic our survey included two questions on awareness of risk factors. First, respondents were asked to identify risk factors for developing AMD from the following list: a) smoking, b) lack of vitamins/nutrients, c) age, d) unprotected exposure to sunlight, e) genetics, f) sex/gender, g) computer games, h) others and k) don't know/no answer. In our analysis we will focus on the answers of those who had stated that they were familiar with AMD. Similar trends apply to those who correctly identified the eyes as the body part affected by AMD.

The results show that age was correctly identified as a risk factor by the highest percentage of respondents (62 per cent) followed by genetics/family history with 44 per cent. As we have seen above these are the main unmodifiable factors that increase the risk of developing AMD. Since we cannot change them they do not play any role in prevention of AMD (at least as long as there is no gene therapy to change our genetic makeup). Nonetheless, awareness of these risk factors is important since people in these categories should take early detection particularly seriously. We feel that these results reflect an adequate level of understanding of AMD as a condition that mainly affects older people. However, given the up to seven-fold increased risk of developing AMD for people with a family history of it, more needs to be done to raise awareness of the genetic element in AMD.

By contrast, the results demonstrate a worrying lack of awareness of the main modifiable risk factor that has been proven to cause AMD: smoking. Only 32 per cent of respondents who were aware of AMD named this risk factor. Unprotected exposure to sunlight was equally named by 32 per cent of respondents whereas 36 percent named lack of vitamins and nutrients. Both of these risk factors remain subject to scientific debate, with growing evidence of the importance of nutrition but increasing doubt about the impact of light exposure.

**Figure 3. Awareness of risk factors**



To reflect the importance of smoking as the only established modifiable risk factor our last question asked people whether they thought that smoking can harm their sight.

The results demonstrate that the percentage of people who think that smoking can harm their sight is significantly higher than the percentage of people aware of AMD, the condition caused by smoking. Nonetheless, in the majority of countries (eight out of 14) more than half the population is not aware of the link (see figure 4 below).

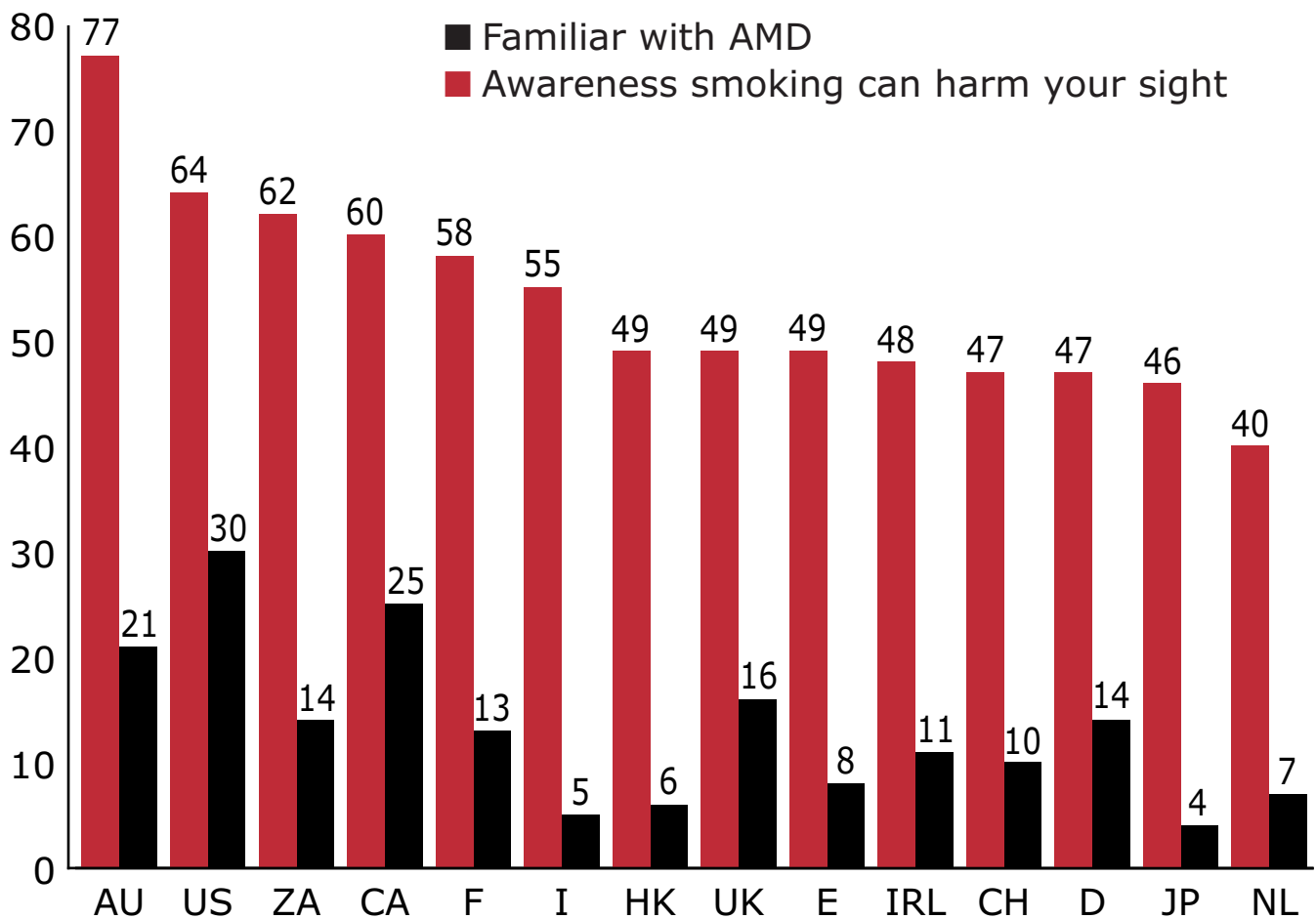
A major exception is Australia, where 77 per cent of respondents are aware that smoking can harm their sight. This is not surprising since Australia is one of the few countries in the world to have mounted a major advertising campaign with hard-hitting pictures to illustrate the harmful effects of smoking on eye health. The campaign has shown that the fear of blindness is a powerful incentive to give up smoking. This is in line with research that has shown blindness to be the disability feared most by people [40]. Hence it is not surprising that calls to stop-smoking hotlines increased in Australia [41] and similar results were seen in New Zealand [42]. As a result of the success of this campaign and on the basis of focus group research Australia has decided to introduce warnings about the link between smoking and blindness on tobacco products from 2006.

Based on these results, we believe that a campaign on the link between smoking and blindness would be a powerful tool to get more people to stop smoking and by doing so avoid the main modifiable risk factor for AMD. Also, the specific references to AMD in public announcements that advertise the link between smoking and eye disease may have contributed to the relatively high awareness rates in Australia (high in comparison to other countries). The gap between awareness of age-related macular degeneration (22 per cent) and awareness of the link between smoking and blindness (77 per cent) merely indicates that long-term, sustained campaigns are required to establish awareness of AMD firmly in people's minds. In other words, it is easier for people to accept the general message that smoking harms your sight than to remember the condition that is caused by smoking.

However, awareness of the link between smoking and blindness is not enough. People need to know more about AMD. Stopping smoking is an important preventative step but equally important is the message about regular eye tests and early detection, given the unavoidable risk factors of AMD.



**Figure 4. Awareness of AMD v. Awareness that smoking can harm your sight**



AU: Australia, US: United States of America, ZA: South Africa  
 CA: Canada, F: France, I: Italy, HK: Hong Kong  
 UK: United Kingdom, E: Spain, IRL: Republic of Ireland  
 CH: Switzerland, D: Germany, JP: Japan, NL: Netherlands

## Section 3: Call for Action

Our survey of 14 countries worldwide clearly demonstrates an alarmingly low level of awareness of the leading cause of visual impairment in the general population. Along with other interested parties we will continue our efforts to raise awareness of AMD among the general population and specific target groups (elderly people, eye health professionals, pharmacists, decision-makers, etc.). However, more extensive efforts are needed to achieve substantial increases in general awareness levels.



**We therefore call on governments to partner with voluntary organizations and other stakeholders to undertake essential large-scale public awareness campaigns on AMD.**

Such campaigns should address two main issues:

- Prevention
- Early detection

Information on AMD and the importance of a healthy lifestyle to maintain eye health should be incorporated in overall government health policies. Since smoking is the only established avoidable risk factor for AMD, the link between smoking and blindness should be incorporated into anti-smoking campaigns with large-scale advertising and warnings on tobacco products. The challenge here will be to ensure that knowledge of the link between smoking and blindness includes awareness of the condition causing vision loss.

Campaigns with a focus on prevention are an important step in the right direction. However, since AMD is not entirely preventable, these steps need to be complemented by action to raise awareness of the importance of early detection. Early detection is crucial to accessing treatment options. Early detection also helps people to adjust gradually to their vision loss and make the most of their residual vision with the help of vision aids. If they access low vision rehabilitation early and particularly if they receive counselling they are much more likely to learn to cope with their vision loss and remain autonomous longer.

There are moral as well as economic arguments for our call for action. It is a moral imperative to prevent blindness and the associated isolation, depression and loss of autonomy. But even without this moral imperative governments need to take account of the very real costs of blindness in terms of direct costs (research, treatment, medication, hospital and nursing home care, etc.) and indirect costs (loss of earnings, vision aids, benefit payments, etc.). For Australia (with a population of 20 million) these costs have been estimated at AUS\$9.8 billion in 2004 alone [43]; for the UK the costs were estimated at £4.9 billion in the same year [44]. Given that AMD is the leading cause of vision loss in developed countries, a considerable part of these costs is attributable to AMD. It is therefore in all of our interests to ensure that AMD is no longer the most common “unknown” cause of blindness.



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## **Annex 1: About AMD Alliance International**

AMD Alliance International is dedicated to raising awareness of age-related macular degeneration (AMD), as well as improving prevention, early detection and access to treatment, rehabilitation and low vision services. The Alliance currently represents organizations in over 20 countries across the globe. The mission of the AMD Alliance International is to bring knowledge, help and hope to individuals around the world affected by AMD.

## **Useful Addresses and Links**

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