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“Cancer and Blindness are the two most feared conditions”

A report on the response to Macular Degeneration Eye Disease in the United States, an invaluable experience made possible by Winston Churchill Trust Fellowship programme.

Sponsored by the Vincent Fairfax Foundation

The annual Vincent Fairfax Churchill Fellowship is for the study of a project to enrich the quality of life for Australians in their advancing years.

Produced by Zenda Curran
October 2003
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  4. Public Prevention, Intervention and Education
  5. Research
Zenda Curran  
Director  
Macular Degeneration Foundation  
GPO Box 4844  
Sydney NSW 2001

Dear Ms. Curran:

The National Eye Institute (NEI) is one of the United States Government’s Institutes of Health. Established by Congress in 1968, the NEI conducts and supports eye research and develops public and professional education programs that help prevent blindness and reduce visual impairment.

Macular Degeneration is the leading cause of blindness and severe vision impairment in the United States. The NEI estimates there are currently more than 1.6 million Americans over the age of 50 who are currently living with the advanced or late stages of macular degeneration.

The NEI supports the prevention, intervention, education, and research of macular degeneration disease.

The Macular Degeneration Foundation of Australia’s effort will make a great difference to the worldwide base of science working to conquer macular degeneration. I wish you and your Foundation the best of success. I would much appreciate staying in contact with you regarding advocating advances in macular degeneration.

Sincerely,

Paul A. Sieving, M.D., Ph.D.  
Director  
National Eye Institute

---

Office of the Director, 31 Center Drive, MSC 2510, Building 31, Room 6A03,  
Bethesda, MD 20892-2510, Phone: 301-496-2234; Fax: 301-496-9970
To Whom It May Concern:

The American Academy of Ophthalmology is the largest national membership association of ophthalmologists. More than 90 percent of practicing ophthalmologists in the United States are Academy members, and the Academy has more than 6,000 international members. The mission of the Academy is to advance the lifelong learning and professional interests of ophthalmologists to ensure that the public can obtain the best possible eye care.

The Academy's Government Affairs Division in Washington D.C. represents ophthalmologists and their patients before federal and state policy makers. Academy staff and physician leaders regularly meet with government officials to provide input on legislative and regulatory issues that affect the delivery of quality eye care, including allocation of funding to the National Eye Institute.

Age-related macular degeneration is currently the leading cause of visual impairment in Caucasians over the age of 50 in the United States, and as in many western countries, retinal eye disease is the major eye health issue facing America today. The Academy has followed this issue in Australia with interest, and we support local efforts to educate in the prevention and intervention of this terrible disease.

The Macular Degeneration Foundation lobbies and educates both state and federal governments in Australia about the need for educational research in preventing and intervening with macular degeneration. Macular degeneration also severely impacts and complicates other eye diseases and is an area that needs to be addressed as a major health priority.

If you have any questions related to macular degeneration and our position, please feel free to contact me in order to discuss this matter further.

Sincerely,

H. Dunbar Hoskins Jr. MD
Executive Vice President
26 June 2003

TO WHOM IT MAY CONCERN

Macular Degeneration is the leading cause of blindness and severe vision impairment in the United States with over 12 million Americans affected by Macular Degeneration.

Each year the MDF USA receives thousands of international inquiries, including inquiries from Australia (2,500 website hits per week). We have welcomed the formation of the peak body MDF Australia in June 2001 to address the important issue of Macular Degeneration in Australia. For many years we have witnessed a demonstrated need for education and support for Australians living with MD.

As a victim of MD, I formed the MDF USA in 1991. This was the first MD not-for-profit organization of its kind in America. Its main objective is to provide funding for research into the disease. It also provides telephone support and education to MD sufferers and other interested parties in the USA.

The MDF USA is an international partner of the MDF Australia. It supports the work of the Foundation in Australia in the prevention intervention education research and support of Macular Degeneration.

I have personally liaised and consulted with Ms. Zenda Curran (Director) for over six years, prior to the formation of the MDF Australia in May 2001.

The MDF USA is closely following with interest the work currently being performed in Australia in relation to the issue of Macular Degeneration.

Yours Sincerely

Ed Aieks
President
Macular Degeneration Foundation Inc
www.eyesight.org

P.O. Box 531313 * Henderson, Nevada 89053-1313
E-mail * ed@eyesight.org Fax * 702-450-3396
Internet * www.eyesight.org
Introduction

Extract 2003 Winston Churchill Annual Report
Zenda Curran- Vision for the Future

In June 2002 the Macular Degeneration Foundation’s founding member and director Zenda Curran was awarded the Vincent Fairfax Churchill Fellowship for the study of a project to enrich the quality of life for Australians in their advancing years.

The process of Macular Degeneration (“MD”) is not easy to understand and the associated medical terms and resources available can be overwhelming. MD is the leading cause of blindness and severe vision impairment in Australia, and its incidence is increasing. More than 800,000 Australians (1 in 7 over 50) have some form of MD yet many do not even know its name, let alone the critical symptoms.

“Make no mistake we are dealing with one of the most devastating forms of eye disease, which now requires an effective national response to the issue” said Ms Curran. Winning the Churchill Fellowship will allow Australia’s MD sufferers to benefit directly from the initiatives being undertaken in the Unites States.

“I'm extremely grateful to the Winston Churchill Memorial Trust and the Vincent Fairfax Foundation for their ongoing support for causes which often go unnoticed. I feel that the award gives recognition to the hundreds of thousands of Australians who have suffered blindness from Macular Degeneration in Australia. Blindness does not and should not have to be inevitable, not in this country” said Ms Curran
Project Description

To investigate and improve knowledge of community, government, academic, innovations, opportunities, research and technology that:

1. Assists and promotes the quality of life of MD patients and carers
2. Educates and assists in the prevention and control of MD in Australians

The study is one of new ideas and innovation and will provide policy recommendations to government in developing a national response to the issue.
Itinerary - North America

- Macular Degeneration Foundation
- American Academy of Ophthalmology
- Eye Care America
- Ophthalmology Fellowship Match
- Lighthouse International
- Macular Degeneration Society New York
- AMD Alliance International
- Canadian National Institute for the Blind
- National Eye Institute
- American Academy of Optometry
- American Optometric Association
1. Macular Degeneration in Australia

1.1 What is Macular Degeneration?

You are reading this page using your macula, the central tiny area of your retina (about 2% of the total retina) which is responsible for your highest visual acuity. Anything that affects the macula will affect your central vision, both distance and close vision, which is needed for “straight ahead” daily activities such as writing, reading, viewing TV, recognising faces, driving, and any other task requiring the fine sharp central field of vision. A person living with the late stages of Macular Degeneration finds these activities almost impossible to perform alone.

Macular Degeneration is a degenerative condition where the macula is progressively damaged, resulting in a loss of central vision. It is the leading cause of blindness and severe vision impairment in Australia and its incidence is increasing.

There is no cure for MD. Treatment options are limited and dependant on the stage and type of the disease. Current treatments aim to halt or slow its progression and preserve as much vision as possible. Any vision loss caused by MD.

1.2 What are the critical symptoms of Macular Degeneration?

Macular Degeneration can cause different symptoms in different people. In its early stages it may go unnoticed as quite often only one eye loses vision first whilst the other eye continues to function normally and compensates for it.

Australians need to be educated that a decrease in vision is not an inevitable consequence of getting older. The need for increased illumination, sensitivity to glare, reading becoming more difficult (print “fading” or “running together”), decreased night vision, and poor colour sensitivity may mean that something is wrong.

The following visual symptoms require urgent attention and should never be dismissed as a symptom of the ageing process:

- **Difficulty** – in reading or doing any other activity which requires fine vision
- **Distortion** – straight lines may appear wavy or bent.
- **Distinguishing** – faces and anything else which requires you to look straight ahead, close up or in the distance is a problem.
- **Dark patches** – or empty spaces appear in the centre of vision.

The early detection of any form of MD is crucial, because any vision lost cannot be regained. Australians over 50 should regularly have their eyes checked at least every two years or as directed by their ophthalmologist.
1.3 Types of Macular Degeneration.

The two most common forms of the late stage of Macular Degeneration are “wet” (exudative) and “dry” (atrophic).

**Wet Form**

The wet form accounts for two thirds of cases in late stage MD in Australia (USA 62%). It causes rapid damage to the macula that can lead to the sudden loss of central vision in a short period of time. This vision loss may be severe.

Wet MD is characterised by the sudden growth of abnormal fragile blood vessels beneath the retina which grow toward the macula. These new blood vessels grow into the retina often leaking blood and fluid under the macula resulting in a permanent scar at the centre of it.

An early visual symptom of wet MD which requires urgent attention is distortion – (i.e. straight lines appear wavy).

**Dry Form**

In the dry form of MD yellow fatty or cell waste deposits called drusen appear around and on the macula. In these cases patches of the retina disappear around the centre of the macula resulting in a gradual loss of central vision.

As an area of the retina becomes diseased there is a slow breakdown of the light-sensing cells in the macula and a gradual loss or blurring of the central vision. Dry MD is different from wet MD does not cause a sudden visual loss or distortion.

If a patient with dry MD experiences any sudden loss of vision, they should see an ophthalmologist. The progression of the disease can be quite rapid or the dry form of the disease can later develop into the wet form.

**Recent Epidemiological Studies**

Public education literature has historically defined the dry form of MD (90%) as more the most common type of MD. Historically there has been no treatment for the advanced stages of dry MD that can prevent vision loss.

Epidemiological studies over the last ten years have resulted in the development of an internationally accepted classification system for the three stages of MD disease. The advanced wet form of MD is now recognised as accounting for about two about thirds of late stage MD in Australia (62% in the USA) and it is responsible for 90% of the severe vision loss caused by MD.

The classification of MD into its various stages of MD will facilitate the development of effective prevention, intervention, control and treatment protocols.
1.4 How common is Macular Degeneration?

The ophthalmology community has agreed upon the international classification of the stages of Macular Degeneration for some time.

Australia:

More than 800,000 (1 in 7 over 50) people in Australia are affected by this disease, whose name they do not even know let alone the symptoms. There are currently 344,000 Australians living with the significant form of MD:

- 108,000 have “late stage” MD (severe loss of vision in one or both eyes), and more than 12,000 new cases will be diagnosed each year². The wet form accounts for two thirds of cases of late stage MD in Australia.

- 236,000 have “significant early stage” MD. Many have vision loss and are at a high risk of progressing to late stage. (They either have many medium sized drusen or one or more large drusen).

An additional 490,000 Australians have “early stage” MD with very early signs of retinal damage. (They either have several small drusen or a few medium sized drusen). Their vision is usually normal.
### Australia Projections 2001
Incidence of MD in Australia - Projections based on the Blue Mountains Eye Study

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Total Popn</th>
<th>Total ARMD Number</th>
<th>000's Early AMD Number</th>
<th>Early AMD 000's</th>
<th>Early AMD %</th>
<th>Stage 000's</th>
<th>Stage 000's %</th>
<th>Significant Lower Risk 000's</th>
<th>Significant Lower Risk 000's %</th>
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<td>1287.7</td>
<td>5.62</td>
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<td>0.00</td>
<td>0.22</td>
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<td>64.20</td>
<td>0.00</td>
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<td>1.12</td>
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<td>75-79</td>
<td>511.0</td>
<td>27.51</td>
<td>140.58</td>
<td>4.49</td>
<td>22.94</td>
<td>9.16</td>
<td>46.81</td>
<td>13.86</td>
<td>70.82</td>
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<tr>
<td>80-84</td>
<td>322.5</td>
<td>33.65</td>
<td>108.52</td>
<td>6.55</td>
<td>21.12</td>
<td>14.49</td>
<td>46.73</td>
<td>12.61</td>
<td>40.67</td>
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<td>85+</td>
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<td>54.57</td>
<td>141.12</td>
<td>19.12</td>
<td>49.44</td>
<td>14.55</td>
<td>37.63</td>
<td>20.90</td>
<td>54.05</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>000's Early AMD Number</th>
<th>Early AMD 000's</th>
<th>Early AMD %</th>
<th>Stage 000's</th>
<th>Stage 000's %</th>
<th>Significant Lower Risk 000's</th>
<th>Significant Lower Risk 000's %</th>
</tr>
</thead>
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<tr>
<td>85+</td>
<td>258.6</td>
<td>141.12</td>
<td>19.12</td>
<td>49.44</td>
<td>14.55</td>
<td>37.63</td>
<td>20.90</td>
</tr>
</tbody>
</table>

**Total**

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Total Popn</th>
<th>Total ARMD Number</th>
<th>000's Early AMD Number</th>
<th>Early AMD 000's</th>
<th>Early AMD %</th>
<th>Stage 000's</th>
<th>Stage 000's %</th>
<th>Significant Lower Risk 000's</th>
<th>Significant Lower Risk 000's %</th>
</tr>
</thead>
<tbody>
<tr>
<td>50+</td>
<td>5490.80</td>
<td>341.30</td>
<td>834.42</td>
<td>1.97</td>
<td>108.26</td>
<td>4.30</td>
<td>235.88</td>
<td>8.93</td>
<td>490.28</td>
</tr>
</tbody>
</table>

**age-sex standardised for the 2001 aust population**
United States:

Dr Paul A. Sieving, M.D. Ph.D, Director of the National Eye Institute acknowledges that “Macular Degeneration is the leading cause of visual impairment and blindness in Americans”.

The pooled data from three international population based eye studies (Beaver Dam Eye Study, Blue Mountains Eye Study, Rotterdam Eye Study) has been examined to provide definitions as to the stages and the prevalence rates of MD.

For the purpose of media communications, the NEI currently quotes the following statistics as to the incidence of MD in the United States:

There are currently 59.3 million people in the United States who are aged 55 or older:

- of which 1.651 million are living with advanced AMD (.960 million having it in one eye and are at a high risk of developing advanced AMD in the second eye).
- Of the 1.651 million 628 million (62%) have advanced dry AMD and 1.023 (38%) million have advanced wet AMD.
- Of the 1.023 million living with wet AMD, 685million (2/3) have wet AMD in one eye and (338 million) 1/3 have wet AMD in both eyes.

There are currently 7.1 million Americans who have intermediate AMD in at least one eye. Of these:

- 4.818 million have intermediate AMD in one eye
- 2.266 million have intermediate AMD in both eyes

Dr Emily Chew is the Deputy Director Division of Epidemiology and Clinical Research for the National Eye Institute and was one of the principal investigators for the Age Related Eye Disease Study 2001. The AREDS data is based on the study of a large cohort (4,757 enrolments) of people who had intermediate and or severe MD. The AREDS data has allowed researchers to examine the possible risk factors that are associated with the progression of MD to its late stages.

Dr Chew indicated that the NEI is currently developing scales based on the AREDS data for the stages and the risk of progression of MD. These scales will examine the different stages of MD, the size of the drusen, drusen area, pigmentation, de-pigmentation, the distance from the macula, etc. Examination of the preliminary AREDS data suggests several possible indicators or factors that can increase a person’s risk of developing late stage MD.

The preliminary data suggests that one of the most important clinical risk factors for the progression of MD is the area that the drusen covers. The greater the area of the drusen the more likely the risk of developing late stage MD. It has also been suggested that there is a high correlation between the area of the drusen and the size of the drusen that can increase a person’s risk of developing late stage MD.
1.5 Economic impact

In the United States and Australia, vision disorders and impairment are major public health problems.

Australia

Of particular concern is the anticipated increase in costs associated with the care and support of a rapidly growing aged population who will suffer from vision impairment and or legal blindness as a result of MD.

Without the provision of an effective program of prevention, intervention education control and support, it is projected that by 2030 that there will be approximately 1.4 million Australians living with MD. The following graph demonstrates the projected increased rate of MD in Australia without intervention.

![Incidence of Macular Degeneration in Australia](image)

Figure 1 Estimated Incidence of Macular Degeneration in Australia. Prof. Mitchell, P University of Sydney 2001 based on projections from the Blue Mountains Eye Study

According to the Australian Institute of Health and Welfare 2001, the average cost per person in Australia for Health and Welfare services in 1999/2000 was $3534. For a person with late stage MD was $16,111. It is projected that the average per annum cost of providing Health and Welfare services to a person with late stage MD by the Year 2030 will escalate to $41,982. See Figure 2.
The Australian Institute of Health and Welfare published separate reports in 2001 estimating the economic cost of health and welfare expenditure per person in 1999/2000 was $3534\textsuperscript{1}.

On current projections and without major intervention, the cost impact of late stage and significant early stage MD will escalate by 2010 to $4.06 billion per year and by 2030 the impact will blow out to over $15.87 billion per year.

United States

Prevent Blindness America has stated “estimates have indicated that the economic impact of visual disorders and disabilities in the USA in 1995 alone approached $40 billion annually, $22.3 billion in direct costs and another $16.1 billion in indirect cost. “

1.6 Social Consequences of Macular Degeneration in Australia\textsuperscript{2}

- Increased mortality
  - Risk of death 1.8 times higher
- Increased morbidity
  - Risk of falls triples
  - Risk of hip fractures nine fold increase
- Increased depression
  - Incidence of depression increases by over 30 per cent\textsuperscript{3}
- Increased social isolation
  - Difficulties with daily living increased two-fold
  - Ease of social functioning reduced by half
  - Religious participation reduced by half
- Use of community services increases 12% with each line of vision lost and overall is increased three-fold by any visual impairment.
The presence of MD is a source of significant disadvantage. Vision is critical to conducting activities of daily living, is a portal for language, and affects developmental learning, communicating, working, health, and quality of life. Vision impairment is one of the most feared disabilities.

People with MD are over-represented among the poor. Their earning power is significantly compromised and as a result there are three times the proportions of people with MD who have incomes in the lowest two income quintiles than people without MD.4

People with MD have a significantly lower workforce participation rate and higher unemployment rate than the general population. In 1998 the workforce participation rate for people with a disability was 53 per cent, as against 76 per cent for people without a disability. Participation rates for people who were blind or vision impaired were even lower — 19 per cent; while the unemployment rate for work force age people with late or significant early stage MD was 70 percentage points higher than for the general population5.

Many people with MD are denied the opportunity to work. For every dollar the Federal Government now spends on Disability Support Pension (DSP) payments, five cents is spent on specialist disability employment assistance. As a result, many working age Australians with MD are denied the opportunities and support they need to work.
1.7 Causes of Blindness in Australia

The Blue Mountains Eye Study

The Blue Mountains Eye Study (“BMES”) examined all people who were 50 years or older, living in two postcode areas west of Sydney, over a period of two years. The BMES is currently conducting the 10-year follow-up study of this cohort.

BMES data projected to 2001, suggest that 34,000 Australians aged 50 years or older are legally blind (< 6/60) in both eyes, 171,000 are blind in one eye and 227,000 Australians have some type of visual impairment (less than 6/12 to 6/60) in both eyes.

Causes of Blindness in Australia (BMES)

MD was found to be the major cause of both blindness (<6/60 in both eyes) (Figure 1) and severe vision impairment (<6/24 and down to 6/60 in the best eye) (Figure 2).

Figure 1- Blue Mountains Eye Study
Causes of Blindness (worse than 6/60 in both eyes)
In Australians aged 50 years or Older.

A few people in the BMES were blind and also had under-corrected refractive error. In these cases MD was the cause of their vision impairment and not their under corrected refractive error. In this group, correcting their refractive error only slightly improved their vision. They still had severe vision impairment even after refractive correction.

In June 2003, Vision 2020 Australia reported that cataract waiting lists are currently an issue in New South Wales. The Greater Metropolitan Task force for Ophthalmology (i.e. committee that reports to the New South Wales Health Minister) is currently addressing the issue of cataract waiting lists in New South Wales.
The BMES found that MD was the major cause of severe vision impairment in Australians.

At this level of vision, the BMES identified some people where under corrected refractive error was a vision problem. These people were encouraged to update their glasses. The BMES found that refractive error was only an important cause of mild vision problems (worse than 6/12 and down to 6/24 in the best eye) in Australians.

In the above category the severe vision impairment caused by the above eye diseases by far out weighed the vision problem of under corrected refractive error by a factor of four to five times.

Under corrected refractive error cannot be compared to the permanent severe vision impairment and blindness that is caused by MD. By the usual definition, people in western countries are considered to be "blind" or "vision impaired" if they do not have "normal vision" after spectacle correction.

Australia is internationally unique with its Medicare system covering optometric consultations. There are also state based programs that provide access to spectacle frames for both the poor and disadvantaged.

**The Fellowship**

The Blue Mountains Eye Study ("BMES") demonstrated that MD is the leading cause of blindness and severe vision impairment in Australia.

All of the organizations visited in North America were unanimous with their verdict. Refractive error is not a major cause of blindness or vision impairment in western countries. However Vision 2020 is seen as an important public health issue with a
particular focus on the eye health issues that face developing countries, and that all
governments globally should support the concept of assisting these nations.

1.8 Most Feared Disabilities and Diseases

It is often stated that “cancer and blindness are the two most feared conditions.” In
the United States, Gallop Surveys were conducted in 1965, 1976, and 1988 regarding

- The most feared major disease
- The most feared disabilities and handicaps

The following questions were asked in the Gallop survey.

Question 1 Fear of Diseases.

*Here is a list of diseases of these which ONE would you say is the worst that
can happen to you? (Note AIDS and Alzheimer’s were not included in the two
earlier survey questions but were added in 1988).*

<table>
<thead>
<tr>
<th>Diseases</th>
<th>1965</th>
<th>1976</th>
<th>1988</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td></td>
<td></td>
<td>50</td>
</tr>
<tr>
<td>Cancer</td>
<td>62</td>
<td>58</td>
<td>17</td>
</tr>
<tr>
<td>Alzheimer Disease</td>
<td>18</td>
<td>21</td>
<td>17</td>
</tr>
<tr>
<td>Blindness</td>
<td></td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>9</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Arthritis</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Polio</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Loss of limb</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Deafness</td>
<td>&lt;1</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

| Percentage          | 100  | 100  | 100  |

(While AIDS and Alzheimer’s were excluded from the 1998 survey, the statistics
remained essentially the same as those for 1976).
Question 2: Fear of Disabilities and Handicaps

Of the following disabilities and handicaps, which ONE would you say is the worst thing that can happen to you? (Loss of memory was added to the questionnaire in 1988).

<table>
<thead>
<tr>
<th>Disabilities</th>
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<th>1988</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blindness</td>
<td>76</td>
<td>42</td>
</tr>
<tr>
<td>Loss of Memory</td>
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<tr>
<td>Muteness</td>
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<td>Deafness</td>
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<td>4</td>
</tr>
<tr>
<td>Loss of smell or taste</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Percentage</td>
<td>100</td>
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</table>
2. A National Prevention and Control Strategy

There is a need for a comprehensive national approach for Australia to respond to the current and future challenges that it will face in response to the Macular Degeneration epidemic. There is no room for complacency, as any vision loss caused by MD cannot be regained.

Recommendation: The Commonwealth Government take a strong leadership role in Australia’s response to Eye Disease.

There is a need for the Commonwealth Government to take a strong leadership role in the development and implementation of an effective National Eye Disease Health Plan.

This plan would rely on active cooperation between the Commonwealth, State and Territory governments, providing the flexibility to respond to the particular demands of eye disease in each jurisdiction while at the same time providing a framework to ensure consistent national standards are maintained.

Recommendation: That the Commonwealth Government address the issue of Macular Degeneration in Australia by developing and implementing a National Macular Degeneration Strategy as part of the National Eye Disease Health Plan.

There is a need for a National Macular Degeneration Strategy, a program for the prevention, intervention, education, treatment control and support of MD sufferers and a national education program for health care professionals.

Australia needs an effective wide ranging response to the MD epidemic including but not limited to the current and future treatment and care needs of people living with MD and the exponential growth in the epidemic itself.

The National MD Strategy should take a whole of government approach that recognises the importance of establishing and maintaining operational links with other national population health strategies; in particular those concerned with national drug policy, the health of the aged and responses to other National Health Priority Areas including cancer control, mental health and cardiovascular health. There are significant opportunities for coordinated efforts in many of these population health areas, including education, prevention and research.

The National MD strategy should includes:

- A national strategy- a whole of government approach
- Linked strategies
- A partnership approach with includes the involvement of affected communities and key health professionals such ophthalmologists and optometrists
- Surveillance, epidemiology and prevention research;
- Targeted research which promotes the highest quality of laboratory and clinical research for MD
Developing and implementing the most appropriate and effective means of prevention, education, treatment, rehabilitation, control, and support including the development of programs, policies, and systems:

- Communication and education;
- Targeted health promotions for the people at the highest risk of developing MD.
- Education of State and Territory Governments so that they comprehend the scope of eye disease in Australia to ensure adequate government resources are devoted to education, treatment, prevention, and control.
- International partnership with organisations such as the National Eye Institute, the American Academy of Ophthalmology, American Optometric Association and the American Academy of Optometry. This is particularly important for all aspects of education, treatment, and research strategies.

Recommendation: That the Commonwealth Government establish an Eye Disease Reference Group as the first step towards developing a National Eye Disease Health Plan.

The Eye Disease Reference Group should play a primary role to the Commonwealth in relation to each eye disease issue. The group should consist of sub-committees for each eye sub-speciality with equal representation from Optometry and Ophthalmology for each sub-committee.

United States History

The National Eye Institute (“NEI”) was established by Congress in 1968 and is one of twenty seven institutes and centres of the Federal Governments National Institutes of Health.

The NEI conducts and supports research that helps prevent diagnose and treat eye disease and other disorders of vision. This research leads to sight saving treatment, reduces visual impairment and blindness, and improves the quality of life of people of all ages. It also develops public and professional education programs that help prevent blindness and reduce visual impairment.

Dr Karl Kupfer was the first Director (1970-200) of the NEI and served in this position for thirty years. In a meeting held with Dr Kupfer he stressed the importance of raising government awareness and involvement in addressing the MD epidemic faced by Australia and other western countries today. Without this support the effective prevention, intervention, treatment, and control of MD will not occur in Australia.

A Strategic Approach

Diabetic Retinopathy was the major cause of blindness in the1960’s. In 1969 the United States Government commissioned 50 prominent ophthalmologists to a historic meeting, held at Airlee House Virginia, to discuss the issue, which like MD today affected a large number of constituents.

Subsequent to this meeting a classification system for the stages of diabetic retinopathy was developed and various interventions were examined as to whether
they could slow down a patient’s progression from one stage of diabetic retinopathy to another stage.

Support from the United States Congress and the Administration in the form of large amounts of funding meant that the NEI could move rapidly in certain areas such as diabetic retinopathy and glaucoma. Dr Kupfer stated that without this support from the United States Government it could have been a number of years before the developments in the prevention and treatment initiatives of these two important areas of eye disease would of occurred.

Recognition of Eye Disease in an Ageing Population

Dr. Paul A. Sieving was appointed as the second director of the National Eye Institute in 2001. He was formerly the Paul R. Lichter professor of ophthalmic genetics and director, Center for Retinal and Macular Degeneration, at the department of ophthalmology and visual sciences, University of Michigan Kellogg Eye Center, Ann Arbor.

Dr Sieving's research at Michigan investigated the genetic basis for retinal and macular degenerations and the basic biology of retinal cells that degenerate and lead to vision loss. He also conducted clinical investigations with individuals who have these conditions and their families, and studies treatments that might slow the degeneration.

An honours graduate of Valparaiso University in history and physics, he completed an M.S. in physics at Yale University and a year at Yale Law School. He went on to receive an M.D. from the University of Illinois Medical School and a Ph.D. in biomedical engineering at the University of Illinois Graduate School. He did his postdoctoral fellowship in retinal physiology at the University of California, San Francisco, with the late Dr. Roy H. Steinberg, and his medical fellowship in inherited retinal degenerations at the Massachusetts Eye and Ear Infirmary, Harvard Medical School, with Dr. Eliot L. Berson.

Dr Sieving has received many awards and honours, including the Senior Scientific Investigator Award from Research to Prevent Blindness, the Alcon Award from the Alcon Research Institute, and he is listed as one of the "Best Doctors in America." He has served on several NIH study sections to review grant applications, and on numerous editorial and advisory boards.

His appointment by the NIH administration in 2001 was in recognition and response to the current challenges faced in the United States in relation to prevention, treatment, and control of eye disease in an ageing population, in particular MD. In a media statement announcing Dr Sievings appointment the NIH stated:

"I am delighted that Dr. Sieving will be assuming the directorship of the NEI," said NIH acting director Dr. Ruth Kirschstein, who made the appointment. "As the nation's population ages, blinding eye diseases will reach epidemic proportions. Dr. Sieving, as an internationally recognized researcher and clinician, will provide dynamic leadership in our efforts to prevent blindness and visual loss."

"I am honoured to be joining the NEI at this important moment when scientific opportunities have never been greater," said Sieving. "I look forward to working with
the NEI staff, the vision research community, and the public to improve eye health for all and quality of life for those with vision impairments.”

In the short time since his appointment Dr Sieving he has been accredited with bringing MD to the forefront of the NEI’s agenda and is currently driving the NEI’s strategic response to the MD epidemic.
3. Some of the Elements of a Prevention, Intervention, Treatment and Control Strategy

3.1 Retinal Ophthalmologists in Australia

Recommendation: The Government needs to examine and provide incentives to address the low number of retinal ophthalmologists who are qualified to treat Macular Degeneration in Australia.

The Royal Australian and New Zealand College of Ophthalmology does not currently keep statistics as to the primary and secondary specialties for its 682 practising members in Australia. It estimates that there are currently 30-35 (including 5 medical retina) ophthalmologists in Australia who are qualified to treat MD disease.

United States Ophthalmology Sub-Specialty

Data from the American Academy of Ophthalmology has indicated that the United States has higher retention rates for retina sub-specialties in comparison to Australia. In December 2002 there were 15,844 practising AAO members in the United States. In March 2003 all members were surveyed with the following responses received:

<table>
<thead>
<tr>
<th>Mar-03 Members Practising</th>
<th>Primary Specialty</th>
<th>Secondary Specialty</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Comprehensive/General</td>
<td>5,631</td>
<td>1,587</td>
</tr>
<tr>
<td>Cataract/IOL</td>
<td>2,277</td>
<td>2,824</td>
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<tr>
<td>Retina/ Vitreous Surgery</td>
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<tr>
<td>Medical Retina</td>
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<tr>
<td>Glaucoma</td>
<td>809</td>
<td>741</td>
</tr>
<tr>
<td>Paediatric</td>
<td>640</td>
<td>741</td>
</tr>
<tr>
<td>Plastic/Reconstructive</td>
<td>529</td>
<td>0.00%</td>
</tr>
<tr>
<td>Refractive</td>
<td>522</td>
<td>1,493</td>
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<tr>
<td>Medical Retina</td>
<td>86</td>
<td>260</td>
</tr>
<tr>
<td>Other</td>
<td>1,448</td>
<td>2,665</td>
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<tr>
<td>Responses Received</td>
<td>13,629</td>
<td>10,087</td>
</tr>
</tbody>
</table>

Winston Churchill Fellowship- Vision For the Future
Page 26
Data from the Ophthalmology Fellowship Match program sponsored by the Association of University Professors of Ophthalmology indicates:

### December 2002

<table>
<thead>
<tr>
<th>Positions Offered</th>
<th>Filled</th>
<th>Still Available</th>
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</thead>
<tbody>
<tr>
<td>Cornea/Ext</td>
<td>02 01 00 99 98 97</td>
<td>02 01 00 99 98 97</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>55 56 56 49 50 60</td>
<td>33 29 38 41 41 41</td>
</tr>
<tr>
<td>Neuro-Ophthalm</td>
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<td>6 5 4 6 6 3 10</td>
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<tr>
<td>Pediatric</td>
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<tr>
<td>Retina</td>
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<td>71 70 57 60 62 56 11 12 16 18 6 14</td>
</tr>
<tr>
<td>Ant Seg</td>
<td>8 9 12 15 13 17</td>
<td>1 7 7 12 9 12 7 2 5 3 4 5</td>
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<tr>
<td>Others</td>
<td>16 13 19 17 20 28</td>
<td>5 2 7 4 5 11 11 12 10 16 23</td>
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<tr>
<td>Total</td>
<td>295 294 289 281 273 289</td>
<td>206 207 206 214 217 200 89 87 83 67 56 89</td>
</tr>
</tbody>
</table>

### Program Participation:

Over the last six years, the number of positions offered, the number of ranks submitted and the percent of applications matched has fluctuated with some trends emerging. There has been a slow upward trend in the number of positions offered overall, primarily due to the increasing number of positions offered in Cornea/External Disease and Retina. The number of positions filled in Glaucoma decreased while the number filled in Retina and Corneal/External Disease increased. Other subspecialties remained the same.

### Applicant Participation:

Applicants are classified by sub-specialties indicated on their rank lists. Some applicants apply to more than one specialty resulting in duplicated counts. The downward trend for Glaucoma applicants has reversed somewhat. Paediatrics and Retina both were experiencing decreases but have bounced back to new highs. Corneal/External Disease and Anterior Segment were markedly up a few years ago.
but have dropped back. In the current match 40% of 3rd year residents matched into a fellowship, the rate continues to rise slowly but surely.

Similar data for Australia is not available. However The Royal Australian and New Zealand College of Ophthalmology has indicated that candidates are encouraged to travel overseas to receive fellowship training in their chosen speciality. RANAZO offers two financial scholarships per annum for this purpose.

![Ophthalmology Fellowships USA - % Filled](image)

3.2 Education for Health Care Professionals.

**Recommendation:** That the Government allocate funding for the development of an national education program (including clinical guidelines for Macular Degeneration) for general practitioners, optometrists, ophthalmologists, and other health care workers.

All ophthalmologists, optometrists, general practitioners and other health care workers, including nurse educators, should have access to appropriate Eye Disease education and development programs.

There are currently no clinical guidelines available for health care professionals in Australia for MD. However there are guidelines for less common eye diseases such as diabetic retinopathy. As there are 30 to 35 retinal sub-specialty ophthalmologists in Australia, provision of clinical educational resources to health care workers (such as optometrists) should be an essential component of any National Macular Degeneration Strategy. The strategy should also include the design and implementation of a national education program about MD for general practitioners, optometrists, ophthalmologists and other health care workers.

There are various clinical resources available from international partners (such as the American Academy of Ophthalmology, American Optometric Association and the American Academy of Optometry) that can be adapted for Australian health care professionals. International partnership and co-operation is an essential component of the strategy.
3.3 The International Revolution of Treatment Regimes

Recommendation: The Commonwealth Government take a strong leadership role in preparing Australia’s response to this century’s revolution in the development and trial of pharmacological drug interventions for the treatment and of MD.

The Eye Disease Reference Group should play a primary role in providing advice to Government in developing its response to each issue.

With the start of this new century there has been substantial progress in the development of pharmacological drug interventions for both the treatment and prevention of late stage MD. New promising pharmacological treatments are currently being trialed internationally.

MD is finally getting the attention it deserves with an impressive number of pharmaceutical companies dramatically increasing research to investigate ways of slowing the progression of MD or decreasing the degree of loss of the central vision. This revolution provides a new set of challenges for Governments internationally.

The National Eye Institute and the American Academy of Ophthalmology have taken a strong leadership role in the international response to the MD epidemic and are working in partnership with ophthalmologists internationally.

The Eye Disease Reference Group should play a primary role in consulting with the Commonwealth Government as to how limited public health dollars can be allocated for treatments which result in the maximum public health benefit.

The Ophthalmology Partnership

Traditionally a majority of ophthalmology treatments have been released into mainstream ophthalmology in the United States before being released in Australia.

The American Academy of Ophthalmology's Government Affairs Division in Washington DC regularly represents ophthalmologist and patients before state and federal policy makers. Academy staff and physician leaders regularly meet with government officials to provide input on legislative and regulatory issues that affect the delivery of quality eye care.

The AAO is regularly asked to provide input on the safety and efficacy of treatments as well as the complexity of procedures associated with those treatments. Following consultation Medicare fee schedules are set for new procedures.

In recognition of the current revolution in treatments for MD, the AAO has adopted a current practice of surveying all of its members practising in the retina sub-speciality, so that a consistent uniform position for the ophthalmology profession can be agreed upon in relation to a particular clinical issue. The AAO recognises the importance of the actual and perceived independence of any committee established to govern that process.
3.4 A Prevention Intervention Education and Control Program

Recommendation: The National Macular Degeneration Strategy should include the design and implementation of a Prevention, Intervention, Education, Treatment, Control and Support Program targeted at MD sufferers in the highest risk population groups.

Primary objectives of this program would include (but would not be limited to) the following:

- To reduce blindness and vision impairment caused by MD through effective prevention, intervention, treatment, and control programs that focus on identified priority areas and specific population groups who are at the highest risk of developing late Stage MD.
- People over 50 to be educated or encouraged to seek regular comprehensive dilated eye examinations at appropriate intervals, which will provide referral links into the early prevention, intervention, treatment, and control programs.
- To assist MD sufferers to make informed decisions as to their treatment options, low vision rehabilitation, and solutions as to living independently.
- Develop and implement targeted public outreach education programs to high risk population groups, including innovative public awareness, education, prevention and control initiatives.
- To develop, implement and promote accessible low vision rehabilitation programs that identify and rehabilitate the living skills that are required by an MD sufferer to manage their vision impairment and live independently.

3.5 Prevention of Macular Degeneration- The Right Focus

Defining the Problem Correctly.

Before any prevention, intervention treatment and control program can be developed, the problem needs to be correctly defined into the stages and types of MD disease.

It is important that patients have a correct understanding about the stage and type of their MD, so with the guidance of their ophthalmologist, appropriate treatment options may be explored.

Public education literature has historically defined the dry form of MD (90%) as the most common type of MD. This is the wrong focus. Historically there has been no treatment available (that can prevent vision loss) for the advanced stages of dry MD.

This historical presentation has been both misleading and confusing to MD sufferers who live with the later stages of MD disease, particularly since the majority of these sufferers have the late stage wet form of MD. In addition mainly sufferers do not realise that the dry form of the MD can rapidly progress into the advanced wet form.

Epidemiological studies over the last ten years have resulted in the development of an effective classification system for the three stages of MD disease. The advanced wet form of MD is now recognised as accounting for about two thirds of late stage² MD in Australia (62%¹² in the USA).
By correctly defining the stages of MD disease it will facilitate the development and trial of effective prevention, intervention, treatment and control protocols for the wet form of MD, which is now accountable for 90% of serious vision loss caused by MD.

The NEI is currently examining preliminary clinical findings from the Age Related Eye Disease Study 2001 for risk factors that can increase a person’s risk of progressing to late stage MD. The NEI is taking a strong leadership role in this process and it is currently working with international partners in response to the MD epidemic.

Laser Surgery

Laser Surgery uses laser to destroy the fragile leaky blood vessels. A high-energy beam of light is aimed directly onto the new blood vessels and destroys them, preventing further loss of vision. The laser treatment may destroy some surrounding healthy tissue and with it some vision, which is why a small percentage of sufferers with the late stage wet form can be treated with laser surgery. Laser surgery is most effective if the leaky blood vessels have initially developed away from the fovea - the central part of the macula. This occurs in about 20% of cases.

There is no cure for MD. Treatment options are limited and dependant on the stage and type of the disease. Current treatments aim to halt or slow its progression and preserve as much vision as possible. Patients living with the wet form of MD need to be educated to attend an ophthalmologist urgently, if they show onset of symptoms such as distortion. In addition the risk of new blood vessels developing after laser treatment is very high and repeated attendances for treatments may be necessary.

Earliest detection of significant early stage MD prior to it advancing to late stage MD would mean that sufferers would present for treatment before they have suffered irreversible vision loss in one eye. A majority of late stage MD sufferers present after they have suffered irreversible vision loss in one or and in some cases both eyes. This is because in its early stages MD may go unnoticed, as quite often only one eye loses vision first whilst the other eye continues to function normally and compensates for it. Patients who have advanced MD in one eye are at an extremely high risk of it developing in the second eye.

3.6 Prevention of Macular Degeneration- Age Related Eye Disease Study (AREDS) 2001

Recommendation- The current cost to the community of MD in Australia is $1.6 billion per annum. The opportunity currently exits to make significant savings in health and welfare expenditure by implementing an effective prevention, intervention, education, treatment, control, and support program which will reduce the number of expected cases of MD by at least 25 per cent.

Finally there is a preventative treatment (the AREDS formula) that can slow the progression of MD (by 25 per cent) from the intermediate stage to the late stage.

Dr Paul A. Sieving, M.D. Ph.D. is the current director of the NEI. In a media release following the AREDS 2001 announcement he stated:
“These nutrients will delay the progression to advanced Macular Degeneration in people who are at high risk….. or those with advanced Macular Degeneration in one eye already.”

The high levels of anti-oxidants are not a cure for MD. They will not restore vision already lost from the disease. However they may delay the onset of advanced AMD and help people who are at high risk of developing advanced AMD keep their vision. People who are at high risk of developing advanced AMD should consider taking the AREDS dietary supplements including those diagnosed by an ophthalmologist as having:

- Intermediate AMD in one or both eyes or
- Advanced AMD

Slowing AMD progression from the intermediate stage to the advanced stage will save the vision of many who would of otherwise had serious vision impairment.

The AREDS Dietary Supplement

<table>
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<th>Ingredient</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitamin C</td>
<td>500 mg</td>
</tr>
<tr>
<td>Vitamin E</td>
<td>400 IU</td>
</tr>
<tr>
<td>ß-carotene</td>
<td>15 mg</td>
</tr>
<tr>
<td>Vitamin C</td>
<td>500 mg</td>
</tr>
<tr>
<td>Zinc oxide</td>
<td>80 mg</td>
</tr>
<tr>
<td>Copper</td>
<td>2 mg</td>
</tr>
</tbody>
</table>

In the 1990’s the NEI recognised the study of high dose zinc and antioxidants as an important public health issue. The use of copper in the formula meant that no participants developed amenia as a side effect of the high zinc doses. There was also no increase in the participant’s cholesterol levels. During the AREDS study the Cancer Institute released results from a study that concluded that high doses of Vitamin A in smokers caused lung cancer. As a result of these findings, all smokers in the AREDS study were given the opportunity to discontinue. Only a small number of participants in the study opted to discontinue the treatment.

Dr Emily Chew, the Deputy Director Division of Epidemiology and Clinical Research for the National Eye Institute, was one of the principal investigators for the AREDS study 2001. Dr Chew stated that the role and effect of Beta Carotene in the AREDS formula couldn’t be ignored, “we simply do not know the answer to that question”.

In the United States there is a smokers and non-smokers AREDS formula that is available for ophthalmologists to prescribe to MD sufferers. The NEI is about to commence another trial in the near future that will focus on the role of Beta Carotene.

The Economic Benefit

While the supplements aren’t a cure for MD in the current absence of an effective cure, individual and collective behaviour change offers the only current means of preventing and controlling the incidence of MD disease, as any vision lost cannot be regained.
The impact of achieving a 25 per cent reduction in the incidence of MD by the year 2010 is dramatic with the per person cost in health and welfare expenditure with late stage MD decreasing by $4,552 and significant early stage by $2,558 per person. The Government has the potential to save over $1.01 billion per year in health and welfare expenditure by the year 2010.

It is estimated that the current impact on the cost to the community of MD in Australia is $1.55 billion and by the year 2010 this will increase to $4.06 billion.

Dr Chew stated that “slowing MD progression from the intermediate stage to the advanced stage will save the vision of many who would of otherwise had serious vision impairment and will result in significant economic savings to governments internationally, including savings on treatments, low vision rehabilitation costs, and the direct and indirect costs to economies resulting from blindness and vision impairment.

The Age Related Eye Disease Study 2001

The ARED study was a major clinical trial over 6.3 years by the National Eye Institute in the United States (4,757 enrolments). The results were published in October 2001 in the journal, Archives of Ophthalmology and showed that high levels of antioxidants and zinc significantly reduce the risk of developing advanced MD by about 25 percent and reduced the risk of vision loss by about 19 percent.

The study was not designed to answer whether high dose antioxidants and zinc are of benefit for those with no signs of MD or those with advanced disease in both eyes. The ten-year follow up study of this cohort continues.

Since the November 2001 announcement, the AREDS formula has been aggressively adopted by the ophthalmological profession in the United States as a preventative treatment that can delay- and possibly prevent- intermediate AMD from progressing to the advanced stage when vision loss occurs. In the United States, there is currently national prime time television advertisements promoting the Bausch and Lomb formula used in the ARED study.
Any National Macular Degeneration Strategy in Australia should examine the practical issues surrounding the accessibility of the AREDS formula and include initiatives that discourage patient non-compliance.

**Recommendation: The National Macular Degeneration Strategy stress the importance of regular comprehensive dilated eye exams at appropriate intervals in order to identify the population who are at a high risk of developing advanced MD.**

Dr Chew stated that one of the important public health messages from the AREDS study is that people over the age of 50-55 who are in the high-risk group for MD, should have regular comprehensive dilated eye exams. It is extremely important that people who are at a high risk of developing advanced AMD are identified.

The United States Health People 2010 Vision program’s first objective is “to increase the proportion of persons who have a dilated eye examination at appropriate intervals”.

Healthy People 2010 is a United States Department of Health and Human Services initiative. It sets a series of health objectives for the United States to achieve over the first decade of the new century.

Healthy People 2010 builds on initiatives pursued over the past two decades. Like its predecessors, Healthy People 2010 was developed through a broad consultation process, built on the best scientific knowledge and designed to measure programs over time. During the public comment period for the draft 2010 objectives an overwhelming public response was received on the issue of Vision impairment.

As a result of mounting public pressure the NEI was commissioned at short notice to draft a new chapter in relation to Vision. In previous decades Vision had not been included as a chapter in this document.

### 3.7 Prevention of Macular Degeneration - Dietary Issues

**Carotenoids**

The National Eye Institute is currently investigating the role of nutrition including the intake effect of lutein and zeaxanthin (carotenoids) on the development and progression of Macular Degeneration.

Dr Chew stated that the NEI considers the study of the relationship between the dietary intake of lutein and zeaxanthin and the risk of developing MD, as an important public health issue. The study will assist health professionals in the future to make dietary recommendations to MD patients.

A number of previous studies have suggested a link between increasing a person’s intake of lutein and zeaxanthin, and decreasing the risk of developing or progressing to the late stages of MD.

Lutein and zeaxanthin are naturally occurring antioxidant carotenoid bio chemicals that are found in green leafy vegetables such as spinach, kale, collard greens, leeks and peas. They are not made in the body and must be obtained from food or dietary supplements.
The theory is that the antioxidant carotenoids (lutein and zeaxanthin) found in the macula, shield or protect the eye from damaging UV rays which can cause free radical damage and eventually lead to the development of MD. With advancing years there is a reduction in the level of these carotenoids in a person’s macula.

In 1994, a NEI supported study indicated that consumption of foods rich in carotenoids were associated with a reduced risk of developing MD. Dr Chew stated that the study had 600 normal (control) participants and 460 participants with advanced wet AMD. The people with the highest levels of carotenoid in their blood had less AMD and appeared to have a greater protection (almost 70% less risk) of developing AMD than people with the lowest level. People with a moderate level of carotenoids had about a 43% reduction risk of having AMD. People with a moderate level of carotenoid had had about 50% reduction risk of developing AMD.

The study also examined the participant’s blood levels of carotenoids to determine what was the most common. Participants who had high levels of Lutein and zeaxanthin in their blood had less AMD. In 2001, data from the Third National Health and Nutrition Examination Survey reported that higher intakes of lutein and zeaxanthin among people ages 40-59 may be associated with a reduced risk of advanced MD.

Conversely, in 1998, the Beaver Dam population study found no significant association between the risk of either early or advanced MD in groups that had either the highest intakes of lutein and zeaxanthin or the lowest intakes of lutein and zeaxanthin.

The NEI has recently conducted a pilot study to observe the absorption of lutein into the bloodstream of people over the age of 60. This preliminary study examined lutein dose responses in participants, to determine the best and safest dose of lutein (10mg) to use in a clinical trial that is due to commence in late 2003. This pilot study was the first step in testing lutein as a possible treatment for MD. The pilot study was not designed to treat MD, its purpose was to help determine the best dose of lutein oral supplements in people over age 60.

The NEI is also currently supporting a study that compares the intake of lutein and zeaxanthin with a person’s likelihood of developing AMD.

**Omega 3**

In discussions with Dr Chew she stressed the importance of any public prevention, intervention, and control strategy for MD examining the role of dietary links, as Governments internationally can achieve significant economic savings from some very simple dietary messages. For example data from the Blue Mountains Eye Study suggested a significant protective association from higher fish consumption (Omega 3) and an increased risk associated with higher consumption of dietary fat.

Eating a balanced diet, particularly fresh fruits and green vegetables, avoiding saturated fat and regular consumption of fish may reduce a person's risk of developing late stage MD.
Smoking

Current smokers were shown in the Blue Mountains Eye Study to have four-times the risk of developing MD, than people who had never smoked or those who had given up smoking. Pooled data from 3 continents found a similar risk. Blue Mountains Eye Study data also indicates that smokers develop the disease about 10 years before non-smokers. While there has been an ongoing media campaign to alert consumers that smoking can cause blindness, due to the lack of public awareness of MD, very few Australians have made the link that smoking can actually cause MD.

Dr Chew stated that the link between smoking and MD was an important finding for scientists internationally who continue to research the possible risk factors for developing MD.

3.8 A Partnership Approach

**Recommendation:** The Commonwealth Government promote an effective partnership approach between all levels of government, ophthalmologists, optometrists, general practitioners, community organisations, the medical, health care and scientific communities and the people living with MD.

**Vision Caucus launched in the United States**

On July 16th, a bipartisan coalition of Congressional Members launched the Congressional Vision Caucus (CVC), dedicated to strengthening and stimulating a national dialogue and policy on vision-related problems and disabilities.

The CVC, co-chaired by Rep. Gene Green (D-TX), Rep. Ileana Ros-Lehtinen (R-FL), Rep. David Price (D-NC), and Rep. Patrick Tiberi (R-OH), will focus on three priority areas: research, prevention/public health, and access to treatment and rehabilitation.

The mission of the CVC is to set forth a national vision strategy which raises awareness that the number of Americans at risk for age-related diseases is increasing as the baby-boomer generation ages; provide better understanding of the personal risk of vision loss and stress the importance of necessary steps to preserve and protect eyesight; inform communities so that they may prepare the treatment and rehabilitation services that will be needed; educate Members of Congress so they comprehend the scope of eye problems in our country; and ensure adequate resources are directed towards the research, prevention and treatment of eye disease.

**National Eye Institute**

The National Eye Institute currently has 66 partner organisations, from which it selects representatives to partner with on selected issues. As it develops its strategies for MD this list will be examined for possible additional future partners.
<table>
<thead>
<tr>
<th>NEI Current Partner Members</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration on Aging, Department of Health and Human Services</td>
<td>1</td>
</tr>
<tr>
<td>Alcon Laboratories, Inc.</td>
<td>2</td>
</tr>
<tr>
<td>AMD Alliance International</td>
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<td>Vision Council of America</td>
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</table>
Elements of a Partnership Approach

Any partnership should be based on a commitment to consultation and joint decision making in all aspects of the development and implementation of a National Eye Disease Health Plan.

The Eye Disease Reference Group should play a primary role in consulting to Government on all aspects of the National Eye Disease Plan, which should take a “whole of government” approach.

In conjunction with all members of the nominated partnership the Commonwealth should:

- Develop and co-ordinate policy for all eye diseases including MD;
- Take a strong leadership role in the coordination of health promotion and public education initiatives so that the public receives consistent eye health messages;
- Develop and promote national standards for best practice in MD health care;
- Monitor and evaluate the National Macular Degeneration Strategy and any changing trends to ensure a rapid response;
- In response to emergent areas of need, commissioning health promotion or policy initiatives that are most appropriately carried out on a national basis;

3.9 Low Vision Resources

Low vision is broadly defined as a visual impairment, not corrected by standard glasses, contact lenses, medicine, or surgery, which interferes with the ability to perform everyday activities. Most people develop low vision because of eye disease.

While there is ongoing research and new treatments that show great promise for the future there is still hope for late stage MD patients for living a better life for today. Tools, training, and resources should be accessible to all late stage MD sufferers in order for them to live full and independent lives despite their vision impairment.

Vision loss can cause more depression than any other physical impairment. This depression does not depend on how much vision is lost, but rather how much function is lost in performing a person’s daily activities. 15

Arelene R. Gordon Research Institute-Lighthouse International

Founded in 1905 Lighthouse International is a leading resource worldwide on vision impairment and low vision rehabilitation. Through its work in low vision rehabilitation services, education, research and advocacy, Lighthouse International enables people of all ages who are blind or partially sighted to lead independent and productive lives.

Social Research from Lighthouse International has shown that people living with blindness or vision impairment are amongst the most disadvantaged members of our community. The research focuses on the impact of vision impairment on daily living and adaptation to vision loss.
A person’s low vision condition is all the more likely to have a negative impact on their financial situation, employment opportunities and they can be discouraged from education and training due to inadequate access to facilities and services for the blind, vision impaired and print handicapped.

As part of Lighthouse programs, an individuals’ adaptation to vision loss is measured via a structured clinical interview both pre and post low vision rehabilitation services. An independent third party then evaluates (on an ongoing basis) the effectiveness of specific low vision programs. Lighthouse International stresses the importance of an evaluation phase for each client prior to accessing low vision services, as many clients do not know what is available and more importantly what services they need to access.

**United States Currency redesigned for the Vision Impaired**

In recognition of the significant proportion of the United States population who are vision impaired, the United Sates Treasury consulted with Lighthouse International in the redesign of its paper currency. Lighthouse International recommended and advocated for the low-vision feature of a large, dark sans serif numeral in a clear field. This low-vision feature has been included on all denominations, as they have been redesigned. The Treasurer of the United States visited Lighthouse International in October 1997 to officially launch the new $50 bill (the first bill redesigned) as it was introduced into currency.

The Treasurer’s visit was in recognition of the Lighthouse's involvement in the review process that produced the new currency bill design. In a press release from the public office of the United States Treasury for the launch of the redesigned $50 bill it stated:

"The Federal Reserve began issuing today, Monday, October 27, redesigned Series 1996 $50 notes. The new notes, which will be widely available in banks and other depository institutions around the world in the coming days and weeks, incorporate new features to protect against counterfeiting and make U.S. currency more easily identifiable to people with low vision"

"The redesigned $50 note and subsequent denominations also will include a large dark numeral on a light background on the back of the note that will make it easier for the more than 3.7 million Americans with low vision to denominate the note. The feature will also be useful to the 10 million Americans with milder forms of visual impairment and other users of U.S. currency in low-light situations. In a January 1995 study solicited by the Treasury Department’s Bureau of Engraving and Printing, the National Academy of Sciences recommended incorporation of the feature.

"The large numeral on the back of the bill will not only help those with low vision to identify a note, it will help everyone who needs to pay for something in low light, such as in a dimly lit bus or taxi cab," Secretary Rubin said.
The Medicare Vision Rehabilitation Bill

Lighthouse International has been committed to advocacy on behalf of people who are blind or partially sighted since its earliest days.

Congress is now considering a landmark bill to thanks to the National Vision Rehabilitation Cooperative — a group comprised of Lighthouse International and other non-profit vision rehabilitation agencies across the country.

Michael Capuano (D, Massachusetts), whose own mother has severe vision impairment and was greatly helped by services provided by Greater Boston Aid to the Blind, recently introduced "The Medicare Vision Rehabilitation Coverage Act of 1999" (H.R.2870) into the House of Representatives. The bill calls for Medicare coverage for the services provided by orientation and mobility specialists and rehabilitation teachers.

National Eye Institute – Low Vision Education Program

The National Eye Institute recognises Low Vision as an important public health issue. The NEI’s Low Vision Education Program helps people to understand what low vision is and explains what steps the vision impaired can take to keep their independence, despite their vision loss.

The NEI’s Low Vision Education program specifically aims to answer the following questions:

- What can people do about their low vision?
- What can they do to maintain their quality of life?
- How can they make the most of their remaining vision?

"The impact of low vision on a person's quality of life can be devastating," NEI Director Dr. Carl Kupffer (the first NEI director 1970-2000) said at the program's launch at the National Press Club in Washington DC. "People with low vision have difficulty with everyday activities, such as reading the newspaper, recognizing familiar faces, or working at their jobs. Many people with low vision become socially isolated because they can no longer enjoy activities such as playing cards or going to a movie. The health of people with low vision may be compromised when they cannot recognize medications or read labels or nutritional information on food packages. Daily life becomes complicated when people are unable to travel alone or lose interest in cooking because the microwave panel or stove dials are hard to see".

"But people should not accept the statement that nothing can be done about their low vision," Dr. Kupfer said. "The fact is that they can do something about it. People with low vision can improve their quality of life through vision rehabilitation services to teach them how to use their remaining vision more effectively. Using a variety of visual and adaptive devices may bring back or help them keep their independence."

Dr. Kupfer said people with vision loss—particularly seniors—tend to accept their condition and not seek help. "Sadly, many older adults feel low vision is a part of aging that they have to accept," Dr. Kupfer said. "But help exists. There are services
and devices that allow people who cannot see well to continue leading independent and full lives."

"We want to take the notion that low vision cannot be helped and replace it with messages of hope," said Rosemary Janiszewski, director of the NEI's National Eye Health Education Program. "We know that people with low vision often feel they have no hope for improving their daily lives and may experience frustration and uncertainty. This can lead to profound lifestyle, physical, economic, and psychological stresses on them and their families.

"Our message is simple," Janiszewski said. "Vision rehabilitation can help bring back independence; home modifications, such as lighting and the use of contrasting colors, can make a difference in daily living; and most importantly, help is available."

The NEI's Low Vision Education Program includes a multimedia public service campaign and a travelling exhibit that will be displayed in shopping malls around the country. The program also provides communities nationwide with materials and technical support to increase awareness of local low vision services and resources.
4. Public Prevention, Intervention, and Education Programs

4.1 The Demonstrated Need in Australia

The MD Foundation USA website receives numerous international inquiries about MD due to the high level of international activity the website has. The MDF USA can currently identify 56% of website activity by country or organisation. For the 2002-03 year there were more than 100,000 identifiable website hits from Australian constituents. In comparison to the populations of western countries outside of America, Australia has consistently demonstrated a high need for public education.

4.2 Low Public Awareness

In January 2003 the results of a large-scale international survey were published in relation to the awareness of age-related macular degeneration in adults:

“Early detection and prompt implementation of appropriate rehabilitation services and therapy can help minimise the long term disability that results from MD.

The level of awareness amongst the general population influences early detection of this disease. Random samples of European and North American populations were interviewed in an international survey designed to assess: the attitudes of people to eye examinations, awareness of the causes of vision loss, awareness of MD, and knowledge of its treatment options.

A total of 7830 adults of at least 18 years were questioned. The main finding was that knowledge of AMD was poor; the majority of respondents were not familiar with MD.
Only 2% of participants knew that MD was the leading cause of severe vision loss in adults 50 years or over, while a majority of those surveyed (75%) was unaware of treatments available for MD.

These results show that there is low international public awareness of MD, which may result in people with MD not receiving prompt medical advice and treatment. There is a need for a wide ranging educational initiative to increase awareness of MD.¹⁴

4.3 Learning from History- The National Eye Institute

Macular Degeneration is a recent epidemic. Over the last thirty years there has been a dramatic shift in the cause of blindness in both the United States and in other western countries. When Dr Karl Kupfer (NEI Director 1970-200) first started in ophthalmology in the early 1950’s, MD was a rarity. In 1970 (first year at the NEI) it was a little more common but still not of the “epidemic” scale faced by the United States and other western countries today.

In the early 1990’s Dr Kupfer first commenced educating the United States Government and the public about this important public health issue as he recognised the United States was “on the verge of a nation wide epidemic”.

At this time one of the main obstacles faced by the NEI was the lack of public awareness about MD despite the fact MD was already affecting a large number of constituents. Relatives and carers of MD sufferers knew that a person had a vision problem, but they had not made the connection that they had someone in their family who had MD. Many people did not even know the name Macular Degeneration let alone the symptoms. This is the same problem facing Australians today.

Since the 1990’s the United States has progressed in its public awareness of MD, mainly due to public health education programs. The AREDS study and the issue of MD has (in comparison to Australia) been aggressively adopted by both the ophthalmological profession and the media. Constituents are much more aware but there is still allot more work to be performed in this area.

National prime television advertisements are currently run by Bausch & Lomb in relation to MD disease and the AREDS formula. The NEI has prepared a number of documentaries on eye health, it actively participates in media opportunities with its partner organisations, and is currently redrafting its patient education material in response to the scientific evidence obtained for MD.
4.4 Health Promotion

Recommendation- The Commonwealth Government design and implement a national public education program as the first stage to an early prevention, intervention, treatment, and control program.

Blindness and visual impairment from MD can be significantly reduced or prevented with early detection and treatment, yet community awareness is alarmingly low and the number of Australians who suffer vision loss from MD continues to increase.

Any MD health promotion initiative should be based on sound social, behavioural and medical retinal research initiatives. The NEI uses science-based evidence as the basis for all of its public education programs.

Any health promotion program developed for Australia should focus on a wide range of activities including those which assist in identifying people who are currently living with MD, for early intervention, prevention, treatment and control, as well as improving the quality of life of people currently living with MD.

MD related prevention and health promotion activities directed at high risk priority groups should incorporate messages about other areas of health for example smoking that causes blindness as well as messages about diet.

National Eye Institute - Eye Health Public Education Programs

As a result of a mandate by congress in 1989 the NEI was first provided with appropriations to develop a formal national education program for diabetic retinopathy and glaucoma. This was a direct result of both constituent pressure and the scientific based evidence that demonstrated that early detection and treatment of these eye diseases could reduce the risk of blindness for people lining with diabetes.

Over the years the NEI Eye Health Public Education program has evolved. Today the NEI develops and implements education programs that help prevent blindness and reduce visual impairment for a number of eye health issues. In his short time as the second NEI Director, Dr Paul Sieving (appointed 2001) has been personally accredited with bringing MD to the forefront of the NEI’s research and public health eye education agenda.

Recommendation: The Commonwealth Government should take a strong leadership role in the Australian response to Macular Degeneration in the context of forming an Eye Disease Reference Group for each identified Eye Disease Public Health Issue.

The NEI has taken the leadership role in the selection and formation of sub-committees for each nominated eye health issue, from its 66 national partnership member organisations. Historically the vision community has worked separately towards their own objectives, rather than working jointly and cohesively together. As all partners agree to the public eye health messages formulated and developed by the NEI, constituents receive consistent messages from a wide range of national organizations. These messages also have the support of credible government sponsored research behind them. The NEI also has the ability to work with several
government agencies when co-ordinating public health messages for issues such as
diet and eye disease.

For each eye health issue or public education campaign the NEI selects a sub-
committee from its 66 national member organisations, forming an umbrella sub-
committee for the relevant issue. The sub-committees are generally comprised as
follows:

- Medical Professionals - ophthalmology, optometry, and physicians if
  appropriate. There is always equal representation from optometry and
  ophthalmology. The NEI approaches the American Academy of
  Ophthalmology and the American Optometric Association to nominate an
  appropriate representative in relation to the specified issue.

- Consumer Representation - representation from consumer organisations or
  constituents living with MD disease in an effort to try and identify national
  organisations that can deliver the message to high-risk constituents.

- Target Audiences within the USA - for example national African American
  community organisations, national African American Women’s groups, and
  various Hispanic organisations

The NEI public eye health education programs are focused on developing, accessing
and delivering messages to high-risk target audiences as opposed to delivering
messages to the general population. This structure has historically been effective in
developing educational materials. As the government co-ordinates the process,
sensitive areas where differences of professional opinion may occur, or issues that
are politically sensitive, can be effectively dealt with and resolved.

The NEI is currently working on the area of AMD and welcomes the international
input and exchange of information in order to develop and update programs. Whilst it
is recognised that Americans have a heightened awareness compared to other
western countries, there is still a lot of work to be done in the area of public
awareness and education.

There is a small planning committee structure that oversees and guides the NEI’s
public eye health communication and education programs. This planning committee
brings expertise to the specific eye disease as well as experience in communications
and public health education. There is equal representation from optometry and
ophthalmology on the planning committee.
5. Research

The exact course of scientific research or rate of discovery for an eye disease as complex as Macular Degeneration cannot be predicted, as it greatly depends on the incremental advances in knowledge that will occur over a period of years.

5.1 The National Eye Institute

The NEI has taken a strong leadership role with its research into MD. Currently more than one third of the total NEI budget is spent on research into retinal degeneration, which includes research into specific retinal diseases, as well as general science based research into retinal degeneration issues (such as the cell biology of photoreceptors and the retinal pigment epithelium).

Over the last five years there has been an increase in the proportion of the NEI budget allocated to specific research for MD disease. The NEI considers the planning and evaluation activities of its research program as essential components of the strategic planning process. As part of this process panels of experts are assembled to review and make recommendations on NEI research programs. These plans are used as vehicles to draw attention to areas of research need and opportunity.

Table NEI Funding History

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<tr>
<th>Year</th>
<th>NEI Funding $Million</th>
<th>$ Million MD Research</th>
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<tr>
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<td>2003</td>
<td>631.8</td>
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Over the last five years the funding allocation by Congress to the NEI reached 88% of its target, to double its funding within that five year period. An increasing proportion of the NEI budget has been allocated to retinal degeneration research and in particular specific research into MD disease. This funding allocation is a significant increase into the area of eye disease, demonstrating US political commitment to the issue.

The annual MD research budget is predominantly spent on research into AMD with some expenditure on the inherited and juvenile forms of MD. This research is specifically on projects targeted at animal models and the human MD condition or on

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a project that ties back to the specific aims of developing a treatment or breakthrough for MD.

Dr. Paul A. Sieving National Eye Institute Director

Dr. Paul A. Sieving was appointed as the second director of the NEI in 2001. He was formerly the Paul R. Lichter professor of ophthalmic genetics and director, Center for Retinal and Macular Degeneration, at the department of ophthalmology and visual sciences, University of Michigan Kellogg Eye Center, Ann Arbor.

Dr. Sieving's research at Michigan investigated the genetic basis for retinal and macular degenerations and the basic biology of retinal cells that degenerate and lead to vision loss. He also conducted clinical investigations with individuals who have these conditions and their families, and studies treatments that might slow the degeneration.

In his short term as NEI Director, he has provided dynamic leadership to the NEI's efforts to prevent blindness and visual loss, and has been accredited with bringing MD to the forefront of the NEI's agenda. In a meeting with Dr. Sieving I asked him where he personally envisaged the future for research into MD. He indicated one of the possible future developments would be in the applied cellular understanding of MD disease. Whilst for example the ARED study results were extremely useful, once of the next steps for scientists would be to study the biology of the macula—Why and how did antioxidants work?.

Dr. Sieving personally encourages and promotes an international base of scientists to provide research into eye disease. Whilst for example Australia's research base may be small in comparison to the United Sates, each independent scientific group researching a particular issue, provides a fresh perspective, which can facilitate an international exchange of ideas and intellectual property.
Recommendation: The Commonwealth Government should allocate more funding for targeted research into Macular Degeneration disease, possibly using the via the existing NHMRC Strategic Research Fund.

National Eye Institute- Deputy Director Dr Jack McLaughlin

The above chart shows actual NEI expenditure for the 2002 calendar year. A significant proportion of the current budget is pent on the area of retina.

The increase in the proportion of NEI budget dollars spent on retinal degeneration and MD research has resulted from a direct initiative of the NEI. Dr McLaughlin stated that over the last six years there has been a consistent drive by the NEI to increase the profile of retinal degeneration research and to specifically increase resources for research into MD disease. The NEI has always recognised research into MD as an important area.

Dr McLaughlin stated that in the early 1980’s the NEI research strategic planning process for MD was very frustrating due to the very few biological or genetic handles for MD that existed in the scientific world, for what was and still is a clinically complex disease. In the early days it was very difficult to attract scientific interest into the MD problem. There were few literature findings, there were no identified biological or metabolic pathways for MD disease, or no real hook to get the scientific community interested in researching the MD problem.

Today research has substantially progressed into areas such as: molecules and genes that may play a role in person’s risk of developing the MD, anti-angiogenesis treatments, and the development of treatment compounds. There are now enough scientific hooks to attract interest from scientists internationally to research the MD problem.
References:

1. Health Expenditure Bulletin No.17 and Welfare Services Expenditure Bulletin No.6

2. Blue Mountains Eye Study, Prof Mitchell P, University of Sydney 2001


8. Beaver Dam Eye Study USA (n = 4756), Rotterdam Study The Netherlands (n = 6411), and Blue Mountains Eye Study Australia (n = 3585).

9. Beaver Dam Eye Study USA (n = 4756), Rotterdam Study The Netherlands (n = 6411), and Blue Mountains Eye Study Australia (n = 3585).


13. Awareness of age-related macular degeneration in adults: the result of a large scale international survey Bruce Rosenthal OD and Bob Thompson BS Optometry Volume 64 January 2003

14. Study “Self Management of AMD and Quality of Life” Archives of Ophthalmology November 2002
