



# MACULAR DEGENERATION NEW ZEALAND

see our vision



**STRATEGIC PLAN** 2010-2012



## **Acknowledgement**

In establishing MDNZ we wish to acknowledge the extensive support, assistance and cooperation of the Macular Degeneration Foundation in Australia.

MDNZ is aligned with international organizations including AMD Alliance International.

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### Letter from the Chairman MDNZ

Macular Degeneration (MD) has been the leading cause of blindness in the over 50 age group. Until recently vision loss was almost inevitable but new treatments for the wet form of MD are now available in NZ. Treatment success is dependent on early recognition and diagnosis, having adequate access to treatment and the availability of the appropriate drug. A recent survey recognized that only 41% of New Zealanders were aware that MD can cause permanent loss of vision and most people did not know the early symptoms. It was timely to develop an organisation in New Zealand which would address the issues of awareness and education as well as providing representation to advocate for access to treatment and appropriate support for those who had already lost vision from MD.

We were inspired by the Australian model of Macular Degeneration Foundation Australia and invited their CEO, Julie Heraghty, to our inaugural meeting in January 2009. From this, a committee and Board of Trustees for MDNZ was elected with representation from the Royal Australian and New Zealand College of Ophthalmologists, New Zealand Association of Optometrists, Royal New Zealand Foundation of the Blind, the macular degeneration community and supporters who have business and corporate experience.

Seven high profile New Zealanders have agreed to be MDNZ ambassadors. We are privileged and grateful for their commitment to our vision.

The Trustees have been assisted by a Medical Advisory Board of ophthalmologists representing six regions of NZ: Auckland, Waikato, Bay of Plenty, Hawkes Bay, Wellington and Christchurch. We are indebted to a number of companies, organisations and individuals who have offered sponsorship and support. This has enabled us to launch MDNZ and to begin to fulfill our objectives with the first awareness campaign travelling from Whangarei to Invercargill.

This strategic plan provides the direction for the first three years, as we develop the five objectives of MDNZ. Age is an inevitable consequence of being alive and we all deserve to retain our independence and quality of life as we age. Through early diagnosis, access to treatment, appropriate intervention and support, MDNZ is here to ensure people with MD have this opportunity.

Yours sincerely,

Dr Dianne Sharp FRACS, FRANZCO  
Chairman MDNZ



# What is Macular Degeneration?

Macular Degeneration (MD) is an eye disease that causes progressive loss of central vision, leading to loss of independence and a reduction in quality of life. It is the leading cause of irreversible blindness in people over 50 in New Zealand and the developed world.<sup>1 2 3 4</sup>

The macula is the central portion of the retina at the back of the eye, enabling central vision and fine detail. In early MD, vision may be mildly affected with slight blurring or difficulty seeing when lighting is dim or there is low contrast.

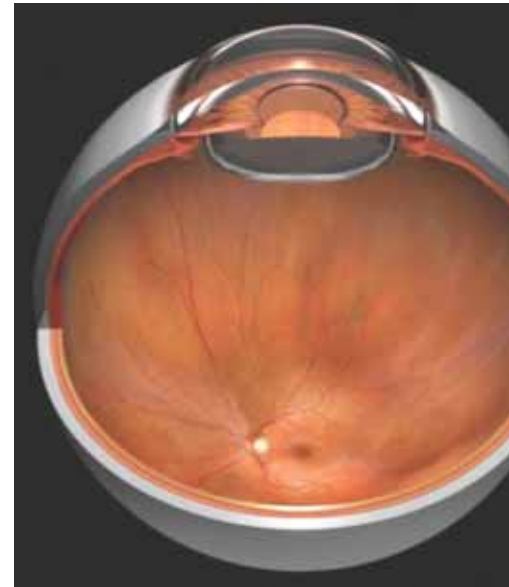
Loss of central vision occurs with more advanced MD, which is either Dry or Wet. Dry or atrophic MD causes thinning of the retina, with a gradual progression over several years.<sup>5</sup> Visual loss depends on the extent and location of the thinning.

Wet or neovascular MD affects two thirds of those with advanced MD but accounts for 90% of those who develop blindness. Abnormal blood vessels growing under the macula may bleed and leak fluid, distorting and destroying vision with progression from normal reading and driving vision to functional blindness. MD tends to occur in one eye at a time but approximately 50% of people will also develop this condition in their second eye within five years and untreated, the majority of people become functionally blind within 2 years.<sup>6 7 8 9</sup>

Loss of central vision reduces the quality of life and is associated with disability and clinical depression in up to one third of people, even if only one eye is affected.<sup>10 11</sup>

Risk factors for MD include advanced age, heredity and a history of smoking.<sup>12</sup>

Current smokers have a risk of developing MD 3 times as frequently and 10 years earlier than nonsmokers or those who have stopped.<sup>13</sup> Nearly two out of three people who live into their nineties will develop MD and one in four will suffer a significant loss of vision from it.<sup>14</sup>



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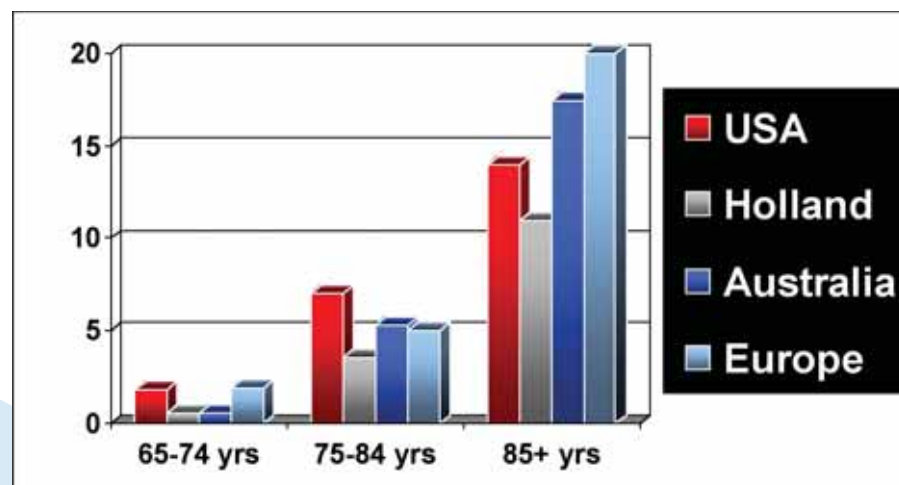
Until recently, treatment of wet MD aimed to stabilize vision and reduce the extent of vision loss however in 2006 clinical trials identified that 90% of patients treated with intravitreal injections of antiVEGF ranibuzimab (Lucentis) avoided moderate loss of vision and over 30% significantly gained vision. <sup>15</sup>

Bevacizumab (Avastin), another anti VEGF agent initially used intravenously for colon cancer, has been used off-label as intravitreal therapy for wet MD. No long term studies or safety data is available but short term studies have shown an improvement in vision similar to the improvement with Lucentis. <sup>16</sup>

While treatments have been identified for wet MD the visual benefit is dependent on early recognition and timely access to treatment.

MDNZ aims to increase awareness of MD, ensure that vision is saved with New Zealanders benefiting from available treatments and ensure that the MD community has access to relevant support services.

### % of Population with Advanced MD





# Macular Degeneration New Zealand

## Who is MDNZ?

Macular Degeneration New Zealand (MDNZ) is a registered charitable trust (#CC42203)

The Board of Trustees represents:

- The Royal Australian and NZ College of Ophthalmologists (RANZCO)
- The NZ Association of Optometrists (NZAO)
- The Royal New Zealand Foundation of the Blind (RNZFB)
- The macular degeneration community
- Business and corporate experience

The majority of Trustees have a substantial personal connection with MD.

### Ambassadors

Dame Kate Harcourt DNZM

Sir Wilson Whineray KNZM OBE

Sir Colin Meads KHZM MBE

Mrs Rosie Horton QSO, QSM

Mr Peter Leitch QSM

Mr John Adshead

Mr Philip Sherry

# MACULAR DEGENERATION NEW ZEALAND

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## STRATEGIC PLAN 2010-2012

### OUR VISION

To reduce the incidence and impact of macular degeneration in New Zealand

### OUR OBJECTIVES

- **Awareness** To increase awareness of MD in the wider community of New Zealand.
- **Education** To provide accurate, specific, current and ongoing information about macular degeneration through education of the MD community, their carers and service providers.
- **Support** To enhance the quality of life of people with MD and the associated MD community, facilitating access to relevant support services.
- **Research** To support and pursue research into the causes, prevention, treatment and possible cures for MD.
- **Representation** To advocate for access to evidence based treatments and advance the best interests of the entire MD community.

### We will achieve our objectives through:

- **Best Practice** in management to ensure a high quality organization
- **High Profile Representation**
- **Fundraising**

### OUR VALUES

MDNZ's Trustees, committees, members, staff and volunteers have common shared values and commitments towards those with MD

- **Respect** for the dignity of the person
- **Compassion**, concern, support and understanding



- **Integrity**, trustworthiness, honesty, loyalty, reliability and the highest standard of ethical behaviour in an environment of total quality care
- **Competency**: Focus on effective, appropriate, high quality care in the advocacy for and administration of services for people with Macular Degeneration, their family and carers

## OUR GUIDING PRINCIPLES

MDNZ's work as a charity aims to meet the real needs of the people it represents and as such operates in the best interest of its client; the MD community. It engages and depends upon the active support of volunteers, individuals and organizations and is guided by the following principles:

### **Access and Equity**

MDNZ is committed to equity of access to treatments, care and rehabilitation.

### **Knowledge**

MDNZ values its knowledge and continues to develop expertise, drawing on its own and others experience.

### **Cultural recognition**

MDNZ is committed to attaining and implementing the dual heritage for the partners of the Te Tiriti o Waitangi (the Treaty of Waitangi) and respecting the cultural diversity of people, encouraging people of all nationalities to utilize MDNZ's facilities and services.

### **Social Justice**

MDNZ pursues social justice and works to empower the MD community and strives to oppose any disadvantage they may be experiencing.

### **Investment**

MDNZ invests in the future by using resources and knowledge to improve the future of the MD community.

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## **STRATEGIC PLAN** *2010-2012*

### **Change**

MDNZ is persistent in pursuing change and works creatively to make a real difference for the MD community.

### **Consideration**

MDNZ respects the client and all those with whom it relates in the meeting of its objectives.

### **Participation**

MDNZ encourages active participation of families, friends and communities.

### **Standards**

MDNZ will uphold the highest ethical standards in its daily work and its relationships with all parties.

### **Appreciation**

MDNZ appreciates the contributions made by Government, advocates, volunteers and other non-government organizations, staff and all who work for the common good of the MD community.

### **Partnerships**

MDNZ will value, support and work with all partners including the medical profession, corporate and allied health care professionals, and national and international agencies to improve the life of people with MD.



# Strategic Themes

## Year 1 LAUNCH AND PROMOTE

### Achieve objectives:

#### Awareness

- Launch MDNZ to increase awareness of MD throughout New Zealand

#### Education

- Vision Van Education Seminars
- Campaigns to encourage early detection of MD and appropriate referral
- Promote factors to reduce risk of MD including diet and stopping smoking

#### Support

- Establish a communication system to be used by the public with an MDNZ website and an 0800 Helpline

#### Research

- Promote the establishment of baseline data on the incidence of MD in NZ

#### Representation

- Create a data base of interested personnel
- Form partnerships for collaboration within NZ (RANZCO, NZAO, RNZFB, Retina NZ, Sight Loss Services) and internationally (MDF Australia and AMD International Alliance)

### Through:

#### Best practice

- Initiate a framework for a strong financial base
- Employ part-time administrator

#### High Profile Representation

- Engage Ambassadors to front promotional work of MDNZ and carry the MDNZ messages to the nation

#### Fundraising

- Establish sponsorship partners
- Develop a comprehensive fundraising plan

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## STRATEGIC PLAN 2010-2012

### Year 2 EDUCATE AND INVOLVE

#### Achieve objectives:

##### Awareness

- Further increase awareness of MD within NZ, collaborating with the medical profession, eye care professionals, low vision specialists and the MD community

##### Education

- Presentation of conference papers at National and regional meetings and information booths at conferences
- Develop data base for rapid dissemination of information and development of regular newsletters

##### Support

- Forge partnerships with healthcare providers (including DHBs and Primary Health Organisations) and allied groups (including RNZFB and Sight Loss Services), to improve access to treatment and support services

##### Research

- Facilitate collaboration with epidemiologists and other groups, including vision 2020, to obtain NZ based data

##### Representation

- Promote timely access for all New Zealanders to appropriate treatments for MD
- Liaise with Government, DHB's and insurance companies re-funding issues regarding treatments
- Extend partnerships with allied organizations within NZ, including Grey Power, Age Concern, Rotary and Lions Clubs, Probus, government organizations

#### Through:

##### Best practice

- Establish an MDNZ office and employ full-time C.E.O./Administrator.

##### High Profile Representation

- Increase links with media and communication outlets
- Extend involvement and the number of Ambassadors throughout NZ

##### Fundraising

- Implement funding initiatives and community involvement through charity events



## **Year 3 ESTABLISH AND EFFECT**

### **Achieve objectives:**

#### **Awareness**

- Recognise the diversity of culture within the MD community
- Organise an MD Awareness week

#### **Education**

- Produce publications of MDNZ in languages which reflect the multicultural nature of the New Zealand population
- Produce publications in appropriate sized print
- Organise a national MD conference

#### **Support**

- Develop regional support groups
- Facilitate access to regional support services including adequate low vision services

#### **Research**

- Utilising current NZ data, collaborate with Government, health insurers and health care providers to create an appropriate source of funding to deliver the most effective treatment and management of MD as it becomes available following appropriate clinical trials

#### **Representation**

- Establish pathways for access to current and effective care based on evidence based management
- Become a strong, effective advocate for MD, influencing policy and political change
- Advance dialogue with Insurance companies regarding funding of treatments and management of AMD

### **Through:**

#### **Best practice**

- Develop positive communication channels with the Government and charities commission re funding and facility development

#### **High Profile Representation**

- Increase professional involvement in MDNZ

#### **Fundraising**

- Increase fund raising to further develop MDNZ objectives
- Increase the support from corporate partners

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## STRATEGIC PLAN 2010-2012




***“We take our sight for granted.  
We don’t expect to lose our ability  
to read, to recognise our friends,  
or to share the joyful expressions  
on our grandchildren’s faces.”***

**Sir Colin Meads**



## **KEY FACTS on Macular Degeneration**

-  **MD is the leading cause of blindness in the over 50 age group in New Zealand.**
-  **MD affects 1 in 7 people over 50 years.**
-  **The prevalence of visual impairment from MD will almost double in the next 20 years.**
-  **Approximately 25,000 New Zealanders are affected with wet MD with up to 800 new cases per year.**
-  **Untreated, the majority of people with wet MD become functionally (legally) blind within 2 years.**
-  **The cost of legal blindness due to increased falls and admission to residential care is \$21,000 per year.**
-  **Visual impairment decreases the quality and length of life.**
-  **There is over 40% higher incidence of depression in MD patients than elderly people without MD.**
-  **50% of people who have MD in one eye will develop MD in their second eye within 5 years.**
-  **Current smokers have 3 times the risk of developing MD and will develop it 10 years earlier.**
-  **Only 41% of New Zealanders know that MD can cause vision loss.**

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## **OUR CONTACTS**

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