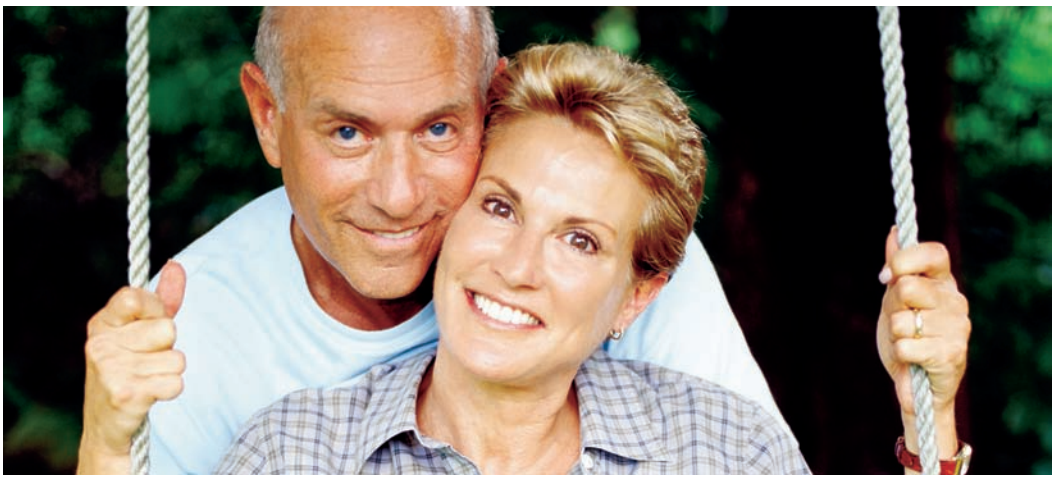
Macular Disease Patient Charter

Each day world-wide, thousands of people are newly diagnosed with macular disease and the numbers are ever increasing in a dramatic way. This must be considered in health sector policy development and in public health programs.

People living with macular disease (MD) have, to the maximum extent they wish, the right to self-determination and an active, informed voice in their life journey with macular disease. The MD Patient Charter is a road map for that patient life journey – written by patients, for patients.

There are four essential cornerstones in this Charter: prevention and cure; timely diagnosis; universal access to proven treatment; and holistic care and support.



1. AWARENESS, PREVENTION AND CURE

People have the right to expect that:

- research into causes and cures is supported by public funding;
- public awareness programs are developed to ensure that awareness of MD as a disease with risk factors is enhanced and action can be taken to reduce risk and future incidence of MD.

All people are entitled to the rights outlined in this Charter regardless of age, gender, marital status, ethnicity, religion, sexual orientation, education or financial status.

2. DIAGNOSIS

People have the right to:

- a timely and accurate diagnosis from qualified and accredited personnel.
- be treated with dignity and respect, which includes receiving timely, supportive and respectful answers to questions.
- receive, at the time of diagnosis, full and complete information about MD, about potential changes in the life journey ahead, and about how to access non-medical resources such as vision rehabilitation and counseling.
- bring caregivers and family into doctor's appointments if they so wish.

3. TREATMENT

Persons with macular diseases have the right to:

- timely care with best possible approved or authenticated treatments.
- make an informed consent to treatment, which means they must be provided with information to ensure understanding about all approved treatment or disease management options, potential benefits, risks and side-effects.

4. CARE AND SUPPORT

People have the right to:

- an optimum standard of care, which includes receiving information about:
  - options for disease management, including follow up eye exams and on-going care.
  - risk management strategies.
  - low vision services and vision rehabilitation, including referral to self-help and professional services such as counseling or other psycho-social services.