Application #18501

INFORMATION

Date Submitted: 23 Jun 2011

Ref#: 18501

Organizational Information

Name of Organization	AMD Alliance International
Country	United Kingdom of Great Britain and Northern Ireland
Type of Organization	Open-ended Working Group on Ageing

Questionnaire/Survey Information

Your organization's FULL NAME *

AMD Alliance International

Purpose of your organization: *

AMD Alliance International is a global consortium of 70 NGO members in senior's, vision rehabilitation, ophthalmology, research, and patient organizations in 26 countries around the world. We exist to provide hope and help for people living with macular disease. Age-related macular degeneration is the leading cause of blindness for older people in the western world and a growing problem in developing nations. The greatest risk factor is age. While people in middle age have about a two percent risk of getting AMD, the risk increases to nearly 30 percent in those over age 75. Worldwide, approximately 30 million people live with AMD.

One of our key objectives is to create awareness of the disease and encourage preventative measures and regular eye exams because compared to people who are sighted, persons with vision loss experience reduced quality of life, greater difficulty with daily living and social dependence, higher rates of clinical depression, twice the risk of premature death, increased risk of falls and related hip fractures and premature admission to nursing homes.

What are the programmes and activities of your organization? They must be relevant to the Open-ended Working Group and the country or countries in which they are carried out. ★

With our broad global reach, and members across wide-ranging political, cultural and geographic spectrums, we play a major role in increasing awareness of macular degeneration with older people around the world, influencing governments to recognize AMD as a health priority, and creating unity. Our activities include:

Creating awareness: AMDAI launches international awareness campaigns focused on older persons and at-risk populations and caregivers to promote the importance of early detection and regualr eye exams for those over 50.

Serving as a global advocate for patients: AMD Alliance mobilizes members around the world to help influence outcomes in many countries and regions to ensure patients have affordable access to the best treatments.

Helping older persons get the care they deserve: AMD Alliance and its members developed the Macular Disease Patient Charter, outlining the rights of people with macular disease. AMDAI encourages governments to embrace the charter and issue national declarations of support. Broad awareness campaigns aim to encourage adults over age 55 to seek the care they deserve.

Developing position papers and reports: AMDAI develops position papers, distributes reports, and recommends actions on important healthcare issues affecting older persons. Recent reports include the Global Cost of Blindness, and classifying wet AMD as a chronic disease.

Keeping patients and caregivers of older persons informed: Through our global public education network, website in four languages (www.amdalliance,org), brochures, newsletters and breaking news alerts, we are helping patients get the information and support they need.

Creating unity: We work to develop channels for resource and knowledge sharing for our 70+ members globally.

Please explain briefly whether your activities are at the national, regional or international level, or a combination thereof. $\frac{1}{2}$

Our activities are a combination of national, regional, and international programmes.

Please attach a scanned copy of an annual report of your organization including financial statements, and a list of financial sources and contributions, including governmental contributions. (PDF or Word only please.)

If you wish, you can provide any additional information on your organization's financial statement here. (Optional)

Please provide a BRIEF list of members of the governing body of your organization, and their countries of nationality; **

Staff

Chief Executive Mr. Narinder Sharma Nottingham (United Kingdom)

Board Members

Chairperson Mr. Hugh Parry Chief Executive Officer Prevent Blindness America (United States)

Vice Chairperson Mr. Tiziano Melchiorrre International Agency for the Prevention of Blindness (Italy)

Treasurer
Dr. Jane Barratt
Secretary General
International Federation on Ageing (Canada)

Secretary
Ms. Julie Heraghty
Chief Executive Officer
Macular Degeneration Foundation (Australia)

Executives at Large
Dr. Keith Gordon
Head of Research
The Canadian National Institute for the Blind (Canada)

Dr. Alan Cruess, Dalhousie University Halifax (Canada)

Mr. Luc Licari Interim Executive Director Retina France (France)

Ms. Lesley-Anne Alexander Chief Executive Officer Royal National Institute of Blind People (United Kingdom)

Immediate Past Chair Mr. MacDonald (Don) Curran (United Kingdom)

Board Members at Large

Mr. Mark Ackermann President and Chief Executive Officer Lighthouse International (United States)

Ms. Helen Jackman Chief Executive Officer The Macular Disease Society (United Kingdom)

Ms. Judith Delgado Director Macular Degeneration Partnership (United States)

Ms. Gretel Schmitz-Moormann Pro Retina Deutschland (Germany)

Mr. Peter Lynch Executive Director Lions Clubs International

Ms. Christina Fasser President

Retina International (Switzerland)

Mr. K. P. Tsang President

Retina Hong Kong (Hong Kong)

Dr. Tracy Williams Executive Director

Spectrios Institute for Low Vision (United States)

Mr. Giusseppe Castronovo

President

International Agency for the Prevention of Blindness (Italy)

Ms. Maryanne Diamond President World Blind Union

Hon. Life Chair:

Dr. Robert (Bob) Thompson

Briefly describe the membership of your organization, including: (a) the total number of members, (b) names of member organizations, if any, and (c) geographical distribution of your membership *

72 Global Members Throughout the World

Argentina Fundación Oftalmológica Hugo Nano Buenos Aires

Retina Brasil São Paulo

Canadian Association of Optometrists Ottawa, Ontario CNIB Toronto, Ontario

Canadian Ophthalmological Society Ottawa, Ontario

The Foundation Fighting Blindness-Canada Toronto, Ontario

International Federation on Ageing Toronto, Ontario

National Coalition on Vision Health Toronto, Ontario

Alliance for Aging Research Washington, DC

Spectrios Institute for Low Vision Illinois

American Optometric Association-Low Vision Rehabilitation Section

Saint Louis, MO

American Society of Ophthalmic Registered Nurses San Francisco, California

The Foundation Fighting Blindness, Inc. Owings Mills, MD

International Association for Audio Information Services Detroit, MI

Lighthouse International New York, New York

The Association for Macular Diseases New York, New York

Lions Clubs International Oak Brook, Illinois

Macular Degeneration Partnership Los Angeles, California

Macular Degeneration Support (MD Support) Grandview MO

Prevent Blindness America Chicago, IL

Alliance for Generational Equity, Inc (AGE) Las Vegas, NV

Macular Degeneration Foundation Henderson, NV

The Hadley School for the Blind Winnetka, Illinois

The Seniors Coalition Washington, DC

Eye Care America San Francisco, CA

Macular Degeneration Foundation Sydney NSW

Retina Australia Thornleigh

Royal Society for the Blind of SA Inc (RBS) Adelaide SA

Australian Blindness Forum Deakin West Act

Vision Australia Enfield NSW

Guide Dogs Queensland Bald Hills, Queensland

Hong Kong Society for the Blind Shamshuipo, Kowloon

Retina Hong Kong

Kowloon

Macular Degeneration Society Singapore Singapore

LV Prasad Eye Institute Banjara Hills, Hyderabad, India

National Society for the Prevention of Blindness - India New Delhi

Retina India Chennai

Retina New Zealand Inc. Raumati Beach

The Royal New Zealand Foundation of the Blind Newmarket, Auckland

Macular Degeneration New Zealand Parnell, Auckland

EURAG: European Federation of Older Persons Graz, Austria

Belgian Organization for the Prevention of Blindness Gent

Finnish Federation of the Visually Impaired Managing Director Helsinki

Retina France Colomiers Cedex, France

Pro Retina Deutschland e.V. Aachen

Berufsverband der Augenärzte Deutschlands Düsseldorf

Fighting Blindness Ireland Dublin

ESHEL: The Association for the Planning and Development of Services for The Aged in Israel Jerusalem

International Federation on Ageing Jerusalem

NAMAG - Association of AMD Patients in Israel Ramat-Hasharon

International Agency for the Prevention of Blindness - Italian Branch Rome, Italy

Retina Italia Onlus Milano, Italy

Società Italiana Retina Rome, Italy

Per Vedere Fatti Vedere Onlus Rome, Italy AMD onlus Rome, Italy Macula Degeneratie Vereniging Utrecht, Netherlands Polish Association of the Blind Warsaw Retina AMD Polska Warsaw **AMD Patient Society** VilniusL, ithuania Retina South Africa Johannesburg Organización Nacional De Ciegos Españoles (ONCE) Madrid, Spain Spanish Vitreous and Retina Society Madrid, Spain Retina International Zurich, Switzerland Retina Suisse Zurich Nadi al Bassar, African Centre for Sight and Visual Sciences Tunis, Tunisia Age Concern England Cannock, UK Fight for Sight London, UK Macular Disease Society Andover, UK Royal National Institute for the Blind London, UK Wales Council for the Blind Cardiff Dr. Bob Thompson, Honourary Life Chair Scarborough Please provide a scanned copy of your organization's constitution or bylaws. (PDF or Word only, please.) If you wish, you can provide any additional information on your organization's constitution or bylaws here.

23 Jun 2011

(Optional)

Please sign off with today's date: **