Awards for Excellence 2015

Mr Ramesh Sivaraj Consultant Ophthalmologist and the macular service team at the Good Hope Hospital, Birmingham won the Clinical Service of the Year award.
Patrons

Henry Blofeld OBE*
Gemma Craven*
Gwyneth Dickinson MBE*
Denis Norden CBE*
Peter Sallis OBE*

Directors, Company Officers & Trustees

Richard Elliott*
Chairman
(retired 25 September 2015)

John Dunston MA, ACIL, FRSA
Chairman
(from 25 September 2015)

Alan Walter*
Vice Chairman

Margaret Packham BSc(Hons), MCIPD, Vice Chairman

Tom Wilson FCA
Honorary Treasurer

Moira Black CBE, MA, FCA
Toby Evans BA(Hons)*
Timothy ffytche LVO, FRCS, FRCOphth

Alison Guthrie  MCOptom
(appointed 24 June 2015)

Lucy Howe FRCOphth

Martyn Long CBE *

Alan MacFarlane *

Paul Ryb BA(Hons) *

Jane Touil BA(Hons), MA *
(stood down 2 December 2015)

Valerie Wares *

Chief Executive & Company Secretary

Cathy Yelf

The rules of the Society require that over 50% of the trustees are visually impaired. The symbol * indicates visual impairment.
Welcome from the Chairman

Welcome to this summary of the annual review of 2015, another extremely successful year in the work of the Macular Society.

I was delighted to accept the role of Chairman in September and very grateful to my predecessor, Richard Elliott, for his leadership of the Society over the last three years. Our Chief Executive, Cathy Yelf, and I look forward to developing the vital work of the Society in supporting people with macular conditions and funding research to find a cure.

My own family knows how important this is: the Society was of immeasurable help when our son was first affected by Stargardt’s macular dystrophy at the age of eight, providing valuable advice, information and support we could not get anywhere else. I was determined then to help this work wherever I could.

This year has again seen an increase in the number of people using the Society’s services. Sadly, the number of people with macular disease is rising.

Age-related macular degeneration (AMD) is by far the biggest cause of sight loss in the UK and the number of people affected is going up as we live longer. There are around 600,000 people with AMD today and by 2050 that number is expected to more than double to 1.3m. Every day nearly 200 people are diagnosed with AMD.

We have continued to expand our services to meet this need and we continue to fund cutting-edge medical research because we must overcome macular disease.

We are so grateful to all our volunteers, members, donors and supporters whose generosity and loyalty enable us to continue this work. Thank you.

John Dunston
Chairman
Supporting people affected by macular conditions

Our services are free and available to anyone who needs them. More than 20,000 people had direct support from the Society in 2015. Many thousands more benefited from our patient information and our website.

- **Helpline calls** – 11,371
- **Counselling sessions** – 921
- **Telephone befriending** – 100 people receive regular calls
- **Local support groups** – 310 with 9,000 members

Some of our services, such as telephone befriending, are provided by volunteers who give their time so generously to help others. We could not provide our range of services without them and we thank them all.

**Local support groups**

Our 310 local groups offer a friendly place for people affected by all forms of macular disease to get together. Groups enable people to give each other support and encouragement, share experiences and provide information.

“The Society helped me through some very difficult times.” Nicola Spearman

“I was told about the Macular Society and received some great support and counselling from them which was very useful.

“I want to raise money so that the Macular Society can continue to contribute towards research into macular conditions so that hopefully one day there may be a cure or treatment for mine.”
Many groups organise fundraising or awareness events, outings, Christmas parties and even holidays. Our groups are run by dedicated volunteers, many of whom have macular disease themselves or are the partners or family of people affected by macular conditions.

We have restructured our volunteering and services department to provide more local support for our network of volunteers across the UK.

Patricia Wickham

“I feel that I’m part of a big organisation which really cares about people and their eyesight.”

Pat joined her local group and later volunteered as group leader. She said: “I came on the first Thursday of October and had such a warm welcome. Everything they were talking about related to me.”

Wigan support group
Trusted information

The provision of trusted, high-quality information about macular conditions is a key function of the Society. In the year we distributed more than 300,000 information leaflets covering every aspect of macular disease including treatment regimens and visual hallucinations (Charles Bonnet syndrome).

We also used our regular email newsletters to subscribers, our website and a growing following on social media sites to communicate with supporters and the wider public.

We held seven successful ‘Top Doctor’ events around the UK with talks from leading clinicians and researchers. We are grateful to the Royal College of Ophthalmologists for once again being our valued partner for these popular events which were attended by over 1,000 people.

Our annual conference and AGM in London was a busy event with more than 450 people attending.

Right: Mr Martin McKibbin, Consultant Ophthalmologist, speaking at the 2015 London Conference.
Members – the heart of the Society

Our members are at the very heart of the Macular Society. We had 15,874 voting members at the end of 2015, 5,772 non-voting eye care professional members and 4,000 members of local groups who are not members of the national Society. Joining the Society means being part of a vibrant and energetic family that supports and campaigns for people with macular conditions. Our strong and growing membership base gives us a powerful voice. Being a member also helps people stay up to date with all the latest information and advice about macular disease and the research going on around the world to find new treatments and a cure.

“I’ve been a member of the Macular Society for less than a year and have had so much help.”  Cecilia Sharp

“I went for over a year being unable to see, losing the colours and shapes of objects. I became very depressed about it all but thanks to the Macular Society I have found the advice has been tremendous.”
Campaigning and raising awareness

Our 2015 campaigns centred on raising awareness and improving access to treatments.

We launched our first ever Macular Week in June and were delighted with the response from our groups and supporters who held events and helped spread a ‘Love Your Eyes’ health message.

We were grateful to Vision Express and many other eye care professionals and hospitals for their support.

Anti-smoking campaign

A second phase of our anti-smoking campaign aimed at young people attracted a large audience on the schools’ website Vivo.

165,237 students visited the Macular Society hub on the Vivo site.

3,272 hours were spent on the hub by the students.

22,262 students completed one or more of the tasks set as part of the campaign.
We campaigned around the country where patients reported they had difficulties accessing timely hospital care. People with wet AMD are especially badly affected by delayed treatment as it leads to irreversible sight loss.

**Excellence celebrated**

Our seventh annual Awards for Excellence were presented at our London conference and provided us with the opportunity to thank the many excellent eye care professionals and marvellous volunteers who do so much for people with macular conditions.

Society Chairman, John Dunston, with Alice Roberts, winner of the Support and Community Rehabilitation of the Year Award.

Helpline team staff member Rosalyn Napper

“It was tremendous. I spoke to Rosalyn on the helpline and she was amazing.”

Jill Davies

Jill called the Society’s helpline after being diagnosed with macular hole (a tear in the macula). She faced a 32 week wait for an operation. Rosalyn, a member of our helpline team, helped Jill by writing to the hospital and shortly afterwards Jill heard that her operation had been brought forward. Since the operation Jill has already seen an improvement in her vision.

She said “A double decker bus had looked like a butterfly to me and faces looked like aliens. It was horrible, it really was. If I had had to wait for the operation my eyesight would be a lot worse than it is now. Rosalyn has been amazing.”
The search for a cure

The Society again funded world-class, innovative research.

A £100,000 grant from the Macular Society to the London Project to Cure Blindness, given in 2008 to develop a stem cell therapy for AMD, has now progressed to a human trial. The lead scientist, Professor Pete Coffey announced at the Society’s London conference that the first patient had been treated. The results of this early-stage trial are expected in the course of 2016.

We commissioned Professor Norman Waugh and Dr Pamela Royle of Warwick University to examine the standard of Macular Society funded research. They reported that it is of high quality and published in respected medical journals.

We also began work on a major campaign document making the case for more public funding of macular research. Our report, Age-related macular degeneration: collaborating to find a cure, will be published in 2016. We are very grateful to the Clothworkers’ Foundation for their support for this project.

PhD student Ellie Keeling examining RPE cells at the University of Southampton.
Our commitment to funding the brightest talent includes sponsorship of PhD students who will help us in finding a cure.

Ellie Keeling is a PhD student at the University of Southampton. She graduated in Neuroscience and is working with Dr Ratnayaka in the Department of Clinical and Experimental Sciences. Ellie is working on the cell biology of the retinal pigment epithelial (RPE) cells and why they fail in AMD. Ellie said: ‘I find working on Dr Ratnayaka’s project motivating and exciting as it combines vision with degenerative disease.’

‘Support from the Macular Society enables this vital research and paves the way to developing more effective treatments against advancing sight loss.’

Dr J Arjuna Ratnayaka, University of Southampton

Timos Naska is a PhD student at Queen’s University, Belfast. After a Masters Degree in Clinical Ophthalmology and Vision Research, he joined Dr Ruth Hogg’s team for his PhD. Timos is investigating how common so-called “reticular pseudodrusen” are within the general population, how they are associated with AMD and what other health problems or lifestyle factors they commonly exist with.

‘Support from the Macular Society has enabled us to get more value out of our ongoing work which is looking at ageing to answer the questions most relevant to our understanding of AMD.’

Dr Ruth Hogg, Queen’s University, Belfast
Fundraising for progress

We rely entirely on voluntary donations. Our work simply wouldn’t be possible without the generosity of our volunteers, supporters, members and partners. Thank you to everyone who helped in 2015.

Our total income was £3,759,000. This includes the restricted income of the local groups that operate under our charity numbers.

We are immensely grateful to every single person who helped us reach that total. People like Edward Beresford-Bolton who ran from John O’Groats to Land’s End as a thank you for our support and advocacy after his diagnosis with AMD. Edward raised over £20,000.

40% of our income is from gifts in wills. Without these gifts, we could not support so many people or fund as much research to find a cure.

Among those remembering us in 2015 was Diana Whybrew, a keen amateur violinist. A share of Diana’s estate is now helping us give valuable support and advice through our helpline and counselling. A gift from Joyce Bushby is funding research to improve wet AMD services in a national audit of patient care. Joyce received friendship and support from our Barnt Green Group.

While controversy surrounded fundraising techniques used by some charities this year, we were able to reassure members and supporters that we do not use the methods criticised, such as selling personal data or telephone fundraising.
Our grateful thanks to all our donors including:

- Big Lottery Fund
- Blindcraft Charitable Trust
- Dr Athol Hughes
- Dr Brigitte Hoffmann-Lundgren in memory of Mrs Aexel-Annelene Briggs
- Garfield Weston Foundation
- G C Gibson Charitable Trust
- Masonic Samaritan Fund
- Millichope Foundation
- Mr Edward Beresford-Bolton
- Mr Roger & Mrs Jean Jefcoate
- P F Charitable Trust
- Pilkington Charities Fund
- Simon Gibson Charitable Trust
- Simplyhealth
- Sir Samuel Scott of Yews Trust
- Sovereign Health Care Charitable Trust
- The Brian Mercer Charitable Trust
- The Cazenove Charitable Trust
- The Clare Milne Trust
- The Clothworkers’ Foundation
- The Eveson Charitable Trust
- The Freemasons’ Grand Charity
- The Gannochy Trust
- The Inman Charity
- The Kellett Fund at Community Foundation Tyne & Wear and Northumberland
- The Kirby Laing Foundation
- The Robertson Trust
- The R S Macdonald Charitable Trust
- Three Oaks Trust
- W O Street Charitable Foundation
Financial review

The summarised accounts that follow are not full statutory accounts but a summary of information extracted from those accounts.

Reference to the full statutory accounts and Trustees’ Report should be made for a full understanding of the financial affairs of the Society. These are available from the Chief Executive, Macular Society, Crown Chambers, South Street, Andover, Hampshire SP10 2BN (01264 350551) or on the Society’s website www.macularsociety.org

The statutory accounts, on which the auditors have expressed an unqualified report, were approved by the Trustees on 13 April 2016 and have been submitted to the Charity Commission.

The accounting requirements of the new FRS 102 have been adopted in the preparation of the 2015 accounts. The 2014 comparatives have been restated on the same basis.

The financial statements show a surplus for the year of £257,000 (2014: £16,000). Total funds at the year-end were £3,337,000 (2014: £3,080,000).

Following the surpluses we achieved in 2013 and 2014 we budgeted for a deficit in 2015. In the event several income streams were again ahead of budget and we made a surplus. The implementation of our 2016 priorities will mean that we will be using part of our surplus unrestricted reserves with the result that these reserves will move towards a more realistic level for our longer term needs.

Our spend on charitable activities in 2015 fell by 2.3%. We were intentionally cautious pending clarification of further fundraising regulation which might significantly affect our income.
## Macular Society
Summarised Accounts for year ended 31 December 2015

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<tr>
<th></th>
<th>2015 £000</th>
<th>2014 £000</th>
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<tbody>
<tr>
<td><strong>Income</strong></td>
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<tr>
<td>Legacies</td>
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<td>Donations &amp; unrestricted grants</td>
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<td>883</td>
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<td>Grants for specified charitable activities</td>
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<td>Fundraising events</td>
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<td>Trading &amp; other income</td>
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<td><strong>Total income</strong></td>
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<td><strong>Expenditure</strong></td>
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<td><strong>Charitable activities:</strong></td>
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<td>Sideview &amp; Digest</td>
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<td>Educational information</td>
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<td>Helpline &amp; counselling</td>
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<td>Groups &amp; volunteer co-ordination</td>
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<td>Local group activities</td>
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<td>Low vision</td>
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<td>Research</td>
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<td>Other expenditure</td>
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<td><strong>Total charitable expenditure</strong></td>
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<td>Cost of generating funds</td>
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<td>Net investment (gains)/losses</td>
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<td><strong>Total expenditure</strong></td>
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<td><strong>Net income</strong></td>
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<tr>
<td>- Unrestricted</td>
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<td>(108)</td>
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<tr>
<td>- Restricted</td>
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<td>124</td>
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<td><strong>Total</strong></td>
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<td>16</td>
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<td><strong>Funds and net assets at 31 December</strong></td>
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<tr>
<td>- Unrestricted</td>
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<tr>
<td>- Restricted</td>
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<td>916</td>
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<tr>
<td><strong>Total</strong></td>
<td>3,337</td>
<td>3,080</td>
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