Youngest member of Paralympic Team GB brings home a silver!

Inside this issue...
- Celebrate our 30th!
- Robot gets positive reaction
- A passion for sport
Launched in the UK 10 years ago, Viteyes is now one of the UK’s leading brands of eye health supplements and is widely recommended by many ophthalmologists.

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Sideview

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Inside this issue
I would like to thank you all for making this year even more successful than the last. We’ve increased our professional membership, introduced Mac to the world, funded over £500,000 of research and held another very successful Macular Week.

We have also launched our major new report ‘Age-related macular degeneration: Collaborating to find a cure’. Thank you to all of you who sent the postcards we provided to your MPs, calling for more investment in research into age-related macular degeneration (AMD). Alongside these efforts we took copies of the report to the party conferences in September. More information on this can be found on page 6.

Next year we will be celebrating our 30th anniversary and we would very much like you to get involved. Our aim is to fund even more research to help us find a cure and expand our vital services. The progress currently being made is immensely encouraging. Please help us celebrate and spread the word so that even more people can benefit from the help and support of the Macular Society. Find out more about our plans to celebrate our 30th year on page 24.

Many thanks as always for your support. On behalf of all the Trustees, may I send to you and yours all good wishes for Christmas and 2017.

John Dunston
Chairman
The Macular Society’s fight for more research funding was taken to the politicians over this autumn. Thousands of members sent postcards to their MPs calling for more investment in biomedical research into age-related macular degeneration (AMD).

Macular Society CEO, Cathy Yelf, and Oswestry Group Leader, Malcolm Johnson, took copies of our research report to the Labour Party conference in Liverpool, handing the report to the former Shadow Secretary of State for Health, Diane Abbott.

Trustee Alan MacFarlane joined Cathy at the Conservative conference in Birmingham to meet Health Minister Philip Dunne and Health Select Committee member Maggie Throup.

The report, ‘AMD: Collaborating to find a cure’, sets out the impact of AMD and the shocking lack of funding for research to find better treatments. In it we revealed that less than one fifth of one per cent of public funding in medical research goes to AMD. This is in spite of the fact that AMD is by far the biggest cause of sight loss in the UK and the numbers of people with it are set to double by 2050.

Total UK research: £3bn
Total directly to AMD: £6m
Less than 0.2%

AMD is the third biggest cause of sight loss globally, with 288m people likely to have it by 2040.
Other major causes of sight loss, such as cataracts and glaucoma, are being conquered while AMD remains incurable and largely untreatable.

Cathy Yelf said: “It’s vital that politicians understand the impact of AMD. We urgently need to invest in medical research now, otherwise many millions of people will lose their sight in the coming decades.

“Big sight loss charities don’t fund medical research so our work is vital both in raising awareness of the need for investment and in actually funding medical research.”

Leading figures support our campaign:

The Rt Hon Lord Blunkett said: “Sight loss brings unique and life-changing challenges. The Macular Society’s report is an important stepping stone towards securing better health outcomes for people and their families following a diagnosis of age-related macular degeneration. It provides a strong platform to generate funding, raise awareness and improve understanding of the far-reaching consequences of this devastating disease.”

Professor Carrie MacEwen, President, The Royal College of Ophthalmologists said: “AMD is the commonest cause of blindness in the developed world and the numbers of patients affected will continue to grow. It must be considered a research priority in order to identify ways to prevent the development of AMD and to treat those affected as early and as effectively as possible. Loss of vision is associated with falls, depression and loss of independence – especially in the older age groups.”

Support the Macular Society’s research fund:

We fund research into AMD as well as inherited dystrophies such as Stargardt’s and Best’s, and Charles Bonnet Syndrome.

Your support is vital if we are to find better treatments and one day a cure for macular disease.

Donate today at www.macularsociety.org/research-appeal
Handheld OCT scanner could reduce waiting times

A new handheld optical coherence tomography (OCT) scanner, which could help to address long hospital waiting times, could be ready by 2018. A prototype of the system is currently being tested at Moorfields Eye Hospital.

Consultant Ophthalmologist, Dr Pearse Keane, gave a presentation on the project at the recent Moorfields annual general meeting.

While still a prototype, the device could one day offer whole-eye OCT, along with other eye examination tests, all in a handheld system.

Trial for dry AMD treatment

A drug that could become the first treatment for dry age-related macular degeneration (AMD) is being trialled in Scotland for the first time. Patients are now starting to receive lampalizumab, which is not yet licensed, as part of a Phase 3 clinical trial. The trial is under way at the Princess Alexandra Eye Pavilion in Edinburgh and Ayr Hospital.

Professor Baljean Dhillon, Consultant Ophthalmic Surgeon with NHS Lothian, is one of 300 doctors across 24 different countries taking part in the study.

New option for macular oedema patients

Pharmaceutical company Bayer’s drug Eylea® will now be offered as a starting point for patients with certain forms of macular oedema.

The National Institute for Health and Care Excellence (NICE) has released a draft recommendation of the anti-VEGF drug for patients with macular oedema, secondary to branch vein occlusion. The drug will need to be sold at a discounted price to meet NICE criteria. This was a turnaround for NICE, after
it recommended Eylea® only as a secondary treatment to the often-painful laser treatments in the provisional guidance documents published in June.

Award for Ophthalmic Surgeon

Professor Geeta Menon, Consultant Ophthalmic Surgeon at Frimley Health NHS Foundation Trust, Surrey has won a National Institute for Health Research (NIHR) Clinical Research Network research award. The award recognises outstanding contributions of NHS consultants and trainees who are active in research, and is run in partnership with the Royal College of Physicians.

Applicants set out how they would use the prize money to increase their contribution to NIHR studies in the future. Geeta said: “Encouraging patient participation in clinical research is crucial to the success of ongoing research activity and its future integration into the NHS.

The prize money will be used to launch an event at the Trust for the public and patients, showcasing the research we currently undertake.”

Treatment centre, first of its kind

A new ophthalmic diagnostic treatment centre for people with AMD in Wales is being launched at a Newport opticians. The centre aims to reduce waiting times for assessment, diagnosis and treatment.

This is the first time in the UK that a high street opticians has been able to provide initial screening and referrals for people with symptoms of wet AMD. NHS staff will also be able to deliver treatment from the same location.

With funding from the Welsh Government, the new centre has been developed through collaboration between Aneurin Bevan University Health Board and Specsavers in Newport city centre.
Macular Society members have helped provide useful feedback to researchers looking at the possibility of robots performing eye surgery.

Dr Christos Bergeles from University College London visited a Macular Society support group to gain an insight into how patients would feel about the development.

Christos (right), who is a lecturer in the department of medical physics and biomedical engineering, posed a number of questions to the Bromley Support Group, including whether they would be willing to be operated on by a robot.

Christos said: “Sight restoration in age-related macular degeneration (AMD) may be possible with novel cell-based therapies that replace the damaged cells in the eye. However, delivery of these treatments, under the retina, is currently performed using a hand-held needle. This is very demanding for surgeons and is at the limit of what can be achieved with conventional surgery, which restricts what success can be achieved.

“This is why we are proposing the development of a tailored, flexible
robotic system, which will be able to perform these more intricate surgeries. They will enable safe, dexterous interventions at the retinal and subretinal layers.”

The idea is that the robot acts like a mechanical hand, which will be guided by the clinician. Expert retinal surgeon Professor Lyndon da Cruz from Moorfields Eye Hospital is collaborating on the project. The robotic device would be designed to eliminate unwanted tremors in the surgeon’s hand, so the surgery can be safely carried out within the eye.

The members were also asked how far they would travel for such a surgery, with many stating they would go as far as they needed to see positive effects on their vision. However, the majority of those asked were not prepared to undergo a procedure that would see them operated on by a robot controlled remotely by a surgeon in another town or city.

The overall reaction from the group was positive and many members would be happy to undergo the procedure as soon as possible, if it would improve their vision.

Christos added: “It is important to gain an insight from patients themselves as they will be the ones undergoing surgery. If they are not happy with what is being developed we need to know now, so this can be addressed.”

Have you done all your Christmas shopping yet?

Raise extra donations for the Society this year. Every time you buy something online and on the high street, you could raise money for the Macular Society at no extra cost to you!

Participating retailers will send us a small percentage on what you spend. It’s easy, just register at: www.easyfundraising.org.uk/macularsociety
Abby Kane, who is just 13, was the youngest member of Team GB at the 2016 Paralympics in Rio de Janeiro. She enjoyed great success, winning the silver medal in the women’s S13 100m backstroke event.

Abby was spurred on to learn to swim after a family holiday to Australia when she was six. On the trip her brother, Fraser, went on all the water park rides but Abby couldn’t as she didn’t know how to swim. On her return she started swimming lessons and began swimming competitively just a year later.

Abby and Fraser both have Stargardt’s disease. Abby said: “I’ve noticed the biggest difference in my vision over the last two years, but it’s not something that bothers me. Stargardt’s hasn’t stopped me from doing anything, in fact it’s...
given me lots of opportunities, especially with my swimming.”

Abby trains six days a week; two hours in the morning followed by an hour and a half in the afternoon. Talking about her journey to reach the Paralympics, she said: “I qualified after competing in trials in April, but I didn’t find out I was going to Rio until May, when I’d spent five days at a training camp for Rio in Manchester. I was so happy, I was buzzing when I was told!

“At the end of August I spent ten days in London training before going straight to Rio. My mum and family also came to Rio. I was staying in the Olympic Village but got to see them at British House, just outside the Olympic Park. The whole experience of being at the Paralympics in Rio was amazing.”

Abby competed in three events – the S13 400m freestyle, 50m freestyle and the 100m backstroke. Speaking about winning her silver medal in the 100m backstroke she said: “I was so happy when I won my medal, I don’t know if what I’ve achieved has completely sunk in.”

Looking forward, Abby said: “I’m training for selection for the World Para Swimming Championships in Mexico next year. And I’d really like to go the Tokyo Paralympics – I’ll be at the best stage in my life.”
NHS-funded study of visual hallucinations

An estimated 2 million people in the UK repeatedly see things that aren’t there. These experiences are known as visual hallucinations and can be caused by sight loss or a range of other conditions.

Many members of the Society have personal experiences of visual hallucinations caused by sight loss, known as Charles Bonnet Syndrome (CBS). Given the number of people affected, surprisingly little is known about CBS or how to treat it, and members often find it difficult to get the information they need.

A large research study, funded by the NHS and led by Dr Dominic ffytche – Study of Hallucinations in Parkinson’s disease, Eye disease and Dementia (SHAPED) – hopes to solve this problem by producing up-to-date treatment guidelines for CBS and visual hallucinations in other conditions.

Society members were the first to volunteer for the study. Some were interviewed by the University of Liverpool, while others took part in a follow-up study with visual and memory tests, and regular telephone calls to check if they’d had hallucinations.

A normal response

Preliminary findings from the study were presented at a meeting in Berlin earlier this year. They show that CBS isn’t caused by problems in the frontal lobes of the brain, unlike in the other conditions, such as Parkinson’s disease and dementia. This means CBS is a normal response of the brain to visual loss, and not an early sign of failing memory or mental illness.

The study will also help plan future large-scale treatment trials for visual hallucinations by finding out whether reducing hallucination
frequency or duration, or changing what you hallucinate is as much a ‘cure’ as stopping hallucinations altogether.

A trial is being planned for next year to explore this issue and the relative benefits of eye-movement, lighting and medication treatments for visual hallucinations. Work on the new guidelines for visual hallucinations is now underway, and the SHAPED study is making steady progress towards its goal of improving support for everyone with visual hallucinations.

Taking part in the study

Society member Barbara Price was diagnosed with dry AMD around nine years ago and started to have CBS hallucinations eight years ago. She said: “I became involved with Dr ffytche’s research in May. I went to London to be interviewed by a researcher and now I get a phone call every three months. I’m asked to describe some of my hallucinations, how often I’ve had them and to explain how they affect my quality of life.

“I’m fascinated by CBS. My hallucinations are very varied and can last anything from a few seconds to a couple of hours, in numerous intermittent spells over several days. I find they can be very intrusive; they come when you don’t expect it and go when they feel like it.

“I always say they are not something to be frightened of – you need to keep clearly in your mind that these images are not real. I find talking about my hallucinations really helps me. I’m very intrigued by them.”

A little owl is one of Barbara’s frequent hallucinations.
Let’s look at screen-reading functions for your mobile phone or tablet. These can give you full control of your technology, regardless of your level of sight.

**Apple (iOS):**
Turn on VoiceOver (Settings > General > Accessibility > VoiceOver). Now place two fingers (or one finger from each hand) on the screen and twist as if turning an invisible dial. This will open the VoiceOver rotor, which you can use to change how VoiceOver works. It will announce items such as ‘headings’ and ‘characters’, which you can select. This is what your device will then look for and read to you when you perform a short, one-fingered vertical swipe.

Imagine you’re in the Notes app and you’ve written a shopping list. Change the rotor to ‘lines’ and then swipe up and down on your device. You will then hear each item in your list sequentially.

If you change your rotor setting to ‘words’ and swipe up and down, it will read the same list one word at a time.
The rotor is very versatile and changing it in different contexts can be extremely beneficial. For example, when you’re on a webpage, if you set your rotor to ‘links’ you can then swipe vertically to move from one link to the next, skipping all the unwanted information in between. You can also set your rotor to ‘characters’ to have email addresses or phone numbers read out one character at a time.

You can add and remove the rotor options by going to Settings > General > Accessibility > VoiceOver > Rotor.

Android:

Download the TalkBack app from the Google Play Store and turn it on. Navigate back to the app you want to use then with one finger, swipe up then right keeping your finger on the screen throughout as if you’re drawing a right-angle. Your device will then announce ‘local context menu’.

If you swipe from left to right with one finger you’ll hear each option in the menu. When you hear the item you’d like to select, double-tap.

The ‘navigation options’ function will take you to a further menu where you can choose ‘words’, ‘lines’ or other options. Then just double-tap when your preference is announced. Subsequent horizontal swipes will navigate around or read out the display as preferred.

Imagine you are in a memo or notes app containing a shopping list. Changing the screen-reader feedback in the local context menu will allow you to read your list line-by-line. Likewise, choosing ‘characters’ from the local context menu would allow you to read a phone number or email address one character at a time.

With TalkBack you also have a global context menu where you can change how your device reads to you. You can choose to hear all items on the screen starting from the top or from the last focussed item, hear the last verbalisation again, hear the spelling of the last verbalisation and many other options.

To access this, with TalkBack enabled, swipe one finger down and right as if drawing a capital ‘L’.
Classic memories

Bernie Graham ran her second ‘Portway Classics’ car show this summer to raise funds in memory of her father. She tells us more.

“We chose to support the Society in memory of my dad, Gerard Murray. Dad struggled for a long time coming to terms with age-related macular degeneration (AMD). In fact, I doubt he ever really did. It forced him to abandon his retirement plans to ‘do some motoring’ and read his vast collection of books on his favourite subjects – classic cars, Formula One and all things motoring. He had to give up driving, but fortunately coach trips kept him and Mam up and about and meeting new people. Dad was a raconteur, he always had a story and, as Mam would say, couldn’t resist embellishment! Gradually though, AMD made it harder for him to communicate with new people – as many of you know, it can be difficult to engage with people if you can’t pick up visual clues and reactions.

“It seemed right that we remember Dad, a man with a lifelong love of cars, with Portway Classics. He would have loved the smell of burnt oil and old leather, and the sound of engineering history, and Mam would have been proud to support him as she always did.

“Even so, it was with some trepidation that we opened our gates to Portway Classics 2016. Even though last year’s event was a roaring success, there was still the underlying fear of the ‘what ifs’. What if nobody turns up? What if we run out of cake? What if it rains?
“Well they did indeed turn up. The Aston Martin Owners Club arrived with both the oldest and newest cars – a 1933 Le Mans and 2012 V8 Vantage S Roadster. The variety of vehicles at the event ranged from a trials-prepared VW Beetle, a 1948 Bristol 400, and a ‘Goldleaf’ Lotus Europa to an Alvis TD21. We also showed a collection of Land Rovers – the earliest, a 1950 80" Series 1, and dedicated a section to upcoming modern classics; the BMW Z3, Mazda MX5s, Porsche Cayman and a 1997 Vauxhall Astra Estate. When did you last see one of those on the road?

“We ran out of nothing, thanks to the fabulous tea ladies and bakers – Lin, Jackie and Barbara – who sold a phenomenal amount of cake, coffee and tea along with jam, chutney and raffle tickets.

“The sun also excelled itself! We enjoyed mellow car-themed music from DJ Gil, a rock covers band and a local Somerset duo playing their unique country cowpunk!

“We look forward to repeating a successful formula next year.”

To remember someone special with a gift in memory call Debbie on 01264 326 620 or visit visionofhope.macularsociety.org
Taking the plunge –
the Serpentine one mile swim

The Serpentine, Hyde Park, London

Huge congratulations to Society volunteer, Sue Smalley, who took the plunge with her husband to fundraise for us at the very first Swim Serpentine mass-participation event in September.

Sue, who has early stage dry age-related macular degeneration (AMD), completed the one mile course in a fantastic 43 minutes and 58 seconds. Her husband Stephen sped round in 33 minutes and 4 seconds. Together the couple have raised over £1,500 for Society funds.

Sue said: “After a lot of training and anticipation, we felt very lucky to be blessed with glorious weather, which made the venue and event even more special.

“Swimming in open water presents its own challenges compared to a swimming pool and can be quite disorientating at times. I found the first bit really hard going, but once I found my pace I was fine. It was my first open water swim and I was very happy to get round in one piece!”

The day was a real family occasion, with daughters Hannah and Laura, and parents John and Pat, cheering the couple on. Sue said: “Swimming in the middle of such an iconic city was an opportunity not to be missed. We had a lovely day together with my parents and our two daughters, who live 160 miles apart.”

The couple only started swimming regularly last year, when they
retired from running their electrical company. She said: “We started swimming in the mornings to get ourselves up. We now both swim three or four times a week.

“To start with, it was just 10 lengths. Then I progressed to half a mile. We both achieved our own personal goals at the event, which were to achieve the mile in front crawl in a reasonable time.”

Sue volunteers as a Skills for seeing trainer and speaker, and first heard about the swim through a Society Volunteering Day.

“My Dad has late-stage AMD, so he was my main inspiration to take part. I’ve been involved with the Society through Dad for the last five years. He started going to the local group and because he can’t drive, I took him along.

“It was quite a coincidence that I was diagnosed about the same time, when I had a scan for something else. Although I have dry AMD, I am still at the very early stages.”

Sue is also involved with a local art class and runs a lunch club, and found plenty of support for her fundraising. She said: “We don’t do this sort of thing regularly, so we weren’t afraid to ask everyone for money.”

“I know any funds we raise will be put to really good use to help fund the Society’s support services as well as research.”
Macular pigment and night vision

A Macular Society funded research project at Ulster University has been studying whether the level of macular pigment (MP) in the eye has any effect on the ability of people with intermediate age-related macular degeneration (AMD) and mild vision loss to see in the dark.

The MP is a yellow, pigmented spot in the centre of the macula. It’s thought to protect the health of the macula by filtering out harmful blue light. The yellow colour comes from a group of substances called carotenoids. Two of the most important carotenoids are thought to be lutein and zeaxanthin. These are yellow plant pigments that give certain foods their colour. Neither of these pigments can be made in the body; they have to be eaten. Green leafy vegetables, such as kale and spinach, contain the highest amounts.

There is interest in the role of MP in AMD, as levels can be improved through a diet rich in green vegetables or by taking supplements. However, we don’t know if differing MP levels have a significant effect on vision when there is mild vision loss and how MP impacts on night vision.

In the study, Dr Raymond Beirne measured how well the eye reacts to low light levels, which is an
indication of the health of the rod cells used to see in the dark. He used an instrument called the AdaptDx®, which measures how quickly the eye recovers after a bright flash of light. The faster the eye recovers, the better the rod cells are working.

The study showed that people with mild vision loss due to AMD have a significantly reduced ability to see in the dark, compared to those of the same age with no AMD. On average it took those with AMD three times as long to recover from a bright light and be able to see in the dark.

However, Dr Beirne didn’t find any significant difference in the amount of MP in those with mild AMD compared to those without AMD. He concluded that by the time there is mild vision loss, the level of MP is not affecting people’s ability to see in the dark.

Dr Beirne also found that measuring people’s ability to see in the dark shows up deteriorating eyesight earlier than the normal tests used in eye clinics.

This research has added to our understanding of the potential role of MP in AMD. It has also shown that measuring the eye’s ability to adapt to low light levels is a more sensitive way to assess the progression of the disease, and a method that could be used to inform treatment and advice to patients in the future.

**Colour vision**

Colour vision in patients with AMD can vary throughout the day due to the damage caused to the cone cells in the retina, which play an essential role in helping us see colour. It is often easier to distinguish between colours when there is a good level of natural daylight as this helps the damaged cones to function better. Distinguishing between colours can be more difficult when natural light levels are lower, or when using artificial light, such as in the morning and the evening.
Celebrate our 30th anniversary next year!

Since the Society was formed by a small group of patients and eye consultants 30 years ago, we’ve helped hundreds of thousands of people living with macular disease. We’ve also remained determined to cure macular conditions and have invested millions of pounds at the forefront of macular research.

Almost 200 million people around the globe have so far lost their sight to age-related macular degeneration (AMD).

If you’re feeling adventurous, or have energetic family and friends, why not sign up for:

- **RideLondon-Surrey 100 Mile Cycle Ride** – this race follows the London 2012 Olympic Road Race Route.

- **Serpentine Swim** – a one mile mass-participation open water swim in scenic Hyde Park, London.

To get involved in fundraising, contact Kathy King on 01264 321 964 or email kathy.k@macularsociety.org
• **Bear Grylls Survival Race** – conquer jungle, mountain, Arctic and desert survival zones in a choice of locations around the UK.

• **Firewalk** – a walk over hot coals! Please check our website for updates on this exciting challenge in the South of England.

If you prefer something a bit more sedate, how about:

• **Tea for MD** – organise a delicious cream tea for family, friends or support group members, or simply get together for a slice of cake and a cuppa. We’ve updated our Tea for MD pack with hints and recipes, balloons, fun cake toppers, bunting and a handy collection box.

• **Fundraise your way!** You might be brimming with ideas on how you’d like to raise money. We’re on hand with advice and promotional materials to help you make the most of your fundraising.

We’re also busy planning **bigger and better Roadshows** for 2017. Come and hear the experts in treatments and research speak at our four larger Roadshows in Edinburgh, Manchester, Bristol or Brighton, with larger exhibitions.

**Don’t forget Macular Week 2017!**

We’re looking forward to Macular Week 2017, which will be held from 26 June to 2 July.

Macular Week 2016 was a huge success with more than twice as many awareness and fundraising events as 2015, including many events at eye clinics and local opticians. We want to make our 30th anniversary year even bigger and better!
Donating eyes for research

Thanks to the generosity of those who donate their eyes for transplantation, each year thousands of people are lucky enough to receive a new cornea and have their sight restored.

The cornea is the clear tissue at the front of the eye, which can become cloudy, distorted or scarred due to accidents, illness or age. A corneal transplant replaces diseased corneal tissue with a disc of healthy tissue from a donor.

A very important benefit of agreeing to donate your eyes is that, with consent, the tissue remaining after transplantation can be used for research. However, there is currently no mechanism for donating eyes just for research. Anyone wanting their eyes to be used in research must consent to becoming a corneal transplant donor as well.

Donated eyes are vital for research into new treatments for eye diseases. The lack of eye tissue for research in the UK is holding back progress towards a cure for diseases like age-related macular degeneration (AMD). Researchers at the University of Manchester have undertaken research on AMD by collaborating with colleagues at The Moran Eye Center in Utah, USA and by using donor eye tissue collected in the USA. Together they have made significant advances in our understanding of AMD, but more research on donor eye tissue is required to develop new treatments.

Age and health are not necessarily barriers to donating. Eyes can be accepted from people up to 90 years old and having AMD wouldn’t exclude someone from
being a donor. However, careful scrutiny of each donor’s medical history is essential in order to assure the safety of any donated organs. Whether or not the eyes or other organs can be used is decided on an individual basis by trained healthcare professionals.

Highly-trained teams remove the eye and restore the facial appearance of the donor. The eyes are then sent to an eye bank, which evaluates and distributes the tissue for transplantation or research.

If you would like your eyes to be used after your death to help restore sight to others and thereafter in research you need to:

- Join the NHS Organ Donor Register. It’s not essential, but if you register it may make granting consent easier for your family when the time comes. The NHS Organ Donor Register can provide up-to-date information on transplant procedures and answer any questions about the process.

- You can join the NHS Organ Donor Register by calling 0300 123 23 23, via your GP or online at www.organdonation.nhs.uk.

- It’s vital to let your family know if you wish to donate your corneas for transplant after your death, as they will be asked for their consent to the transplant. If they say no, the transplant will not take place.

- If you would like your other eye tissue to be used for research, tell your family. They will be asked and may say no if they are not aware of your wishes.

If you live in Wales, the law has changed:

- If you want to be a donor, you can register (opt in) on the NHS Organ Donor Register. Or if you do nothing, you will be regarded as having no objection to donating your organs. This is called deemed consent.

- If you don’t want to be a donor, you can register not to be a donor (opt out) on the NHS Organ Donor Register.
Brian Lee (above) from Belfast, Northern Ireland wanted to celebrate his 80th birthday in style, but when asked about what presents he wanted, Brian said: “What do I want? – nothing! I don’t really need anything. I would much prefer donations to go towards something worthwhile to help people locally.”

So Brian chose donations to the Macular Society instead of presents. His birthday party in October was attended by family and friends, and included a carvery supper and a local band. Brian has had macular degeneration (AMD) for about three years, but gains much support from attending his local macular support group. Talks were kindly given by Eric Wells, a Macular Society volunteer speaker, who spoke about the impact of AMD on people’s lives, and Susanna Beare, an optometrist from the macular department at Mater Hospital in Belfast. Derek Neill, the Chairman of the local group rounded it all up by reading a humorous poem. Approximately £1,000 was raised on the night and this will be shared between our Belfast Macular Support Group and the Society.

Donations in lieu of gifts for any celebration are a great way to raise funds for the Society. We can supply all the materials you need for your celebration, including balloons, decorative banners and gift aid donation envelopes. So if it’s your birthday, anniversary, or even your wedding, please remember the Society by visiting our website at www.macularsociety.org/celebrations, or ring Debbie on 01264 326 620.
We want to hear from you

To celebrate our 30th birthday in 2017 we are looking to share stories from our longest serving members.

If you became a member between 1987 and 1990, and would like to share your journey with the Society with us, we’d love to hear from you.

We are after your memories from the early days and how things have changed for our members in the last 30 years.

If you have any memories to share, please email Sue Stevens at sue.s@macularsociety.org or write to Macular Society, PO Box 1870, Andover, SP10 9AD.

Do you have dry age-related macular degeneration?

Are you interested in taking part in a new research study looking at how vision changes over time in people with dry AMD?

City University London is conducting a study looking at the function of the retina in dry age-related macular degeneration. This is done using an electroretinogram. The electroretinogram is a technique that records electrical signals produced by the eyes in response to flashing lights.

Volunteers will need to visit London three times over the course of 1 year and will be paid £20 to cover travel expenses to and from London for each visit. If you would like to participate, please telephone Angharad Hobby on 020 7040 3226 for more information.
Google helping to revolutionise eye care

NHS patients were recently invited to Google’s offices in Kings Cross, London to learn more about a new medical research partnership. The partnership between Google, Deepmind Health and University College London (UCL) could revolutionise the way professionals carry out eye tests.

The partnership will form an Artificial Intelligence (AI) research lab, based in London. They held a public meeting in a bid to be more transparent with NHS patients about its broader ambitions in healthcare. Founders of the project believe AI could bring huge benefits to medical research, by analysing medical data to find ways to improve how illnesses are diagnosed and treated.

One part of the project involves Moorfields Eye Hospital sharing one million anonymised eye scans. Moorfields has collected these over time through routine care, and have made sure it’s not possible to identify any individual patients.

Elaine Manna speaking at the event.
It’s hoped this will lead to earlier detection and treatment for patients, ultimately helping to avoid new cases of eye diseases, such as age-related macular degeneration (AMD).

“Everyone has got to have hope and I believe that this marriage between UCL, Moorfields and DeepMind Health is going to achieve great things.”

She added: “Everyone was so welcoming and extremely helpful. I had great support from my consultant, Dr Pearse Keane. It was really important for me to get across how it feels to have this condition.”

Elaine, who is 70, was originally diagnosed with wet AMD in one eye in the year 2000. The only option then was laser treatment, which resulted in the complete loss of any remaining vision she had. Ten years later she was diagnosed with wet AMD in the other eye. She was never told this was a possibility. She said: “I just can’t explain how I felt. I was absolutely devastated.”

Another part of the project, revealed at the meeting in London, includes building a patient portal. This will allow patients and doctors to track a patient’s full medical history in chronological order via an app on their smartphone.

For more information on the Google Deepmind partnership visit deepmind.com
A passion for sport

The captain of England and Wales Blind Golf, Steve Beevers, is hoping to encourage more people to get involved in the sport.

Steve has always been passionate about sport, playing cricket from an early age. However, when he was diagnosed with Stargardt’s in his 20s he decided to give it up, as it was becoming too dangerous.

Blind golf was recommended to him by a friend of a friend. He said: “I was told I should give it a go, but I thought at first it was a ridiculous idea. You have to hit a tiny ball and the target is hundreds of feet away!

But I tried it and found out that you have a guide who directs you and gives you as much detail about the course as possible. All you have to do is hit the ball, then there’s the anxious few seconds afterwards before the guide tells you where the ball has gone.”

He added: “We’re all amateur golfers and would love more people to get involved.”

Steve, has now been a member of England and Wales Blind Golf for 11 year and has a handicap of 14. He’s won a number of accolades over the years including the Chairman’s Cup, the English
Strokeplay and the Primary Club Matchplay.

He and his fellow golfers are currently holding open days for others who want to get involved. He said: “I would encourage others to take up blind golf because of the wonderful camaraderie it brings. The opportunity to be active, with friends, in a beautiful environment is too good to miss.”

When Steve was first told he had Stargardt’s he doesn’t remember struggling to come to terms with the diagnosis. He said: “It must have been devastating, but I don’t look back and think I couldn’t do anything. I thought very practically, and I don’t know if that was because it was a gradual thing, but I came to terms with it.”

Having previously worked as a PE teacher, he said the hardest thing would have been not being able to play sport. He said: “All my social and leisure time was sport. I played a lot, including football to a competitive level, cricket and badminton.

“I really enjoy being able to play golf competitively. What I love about golf is that, because you have a handicap, you can play against anyone.”

For more information about blind golf or if you’re interested in getting involved contact Steve at enquiries.blindgolf@gmail.com
AMD and a high fat diet

Age-related macular degeneration (AMD) is a complex condition driven by a person’s genetics, as well as other factors, such as lifestyle and diet. Researchers are still exploring which aspects of your diet may be important, but evidence is emerging that a high fat and cholesterol-rich diet may lead to retinal damage in some people.

Although studies in humans suggest a link between diet and AMD, so far the tools to study these changes have been limited to working with genetically-altered animals or cell culture models.

However, work by Dr Arjuna Ratnayaka at the University of Southampton has shown that normal mice fed a high fat diet have damaged photoreceptors. Similar findings have also been reported independently by a US-based research group, which showed visual defects in mice fed an almost identical high fat diet.

The ability to observe and track eye pathology in mice provides us with a powerful tool to study how retinal damage can be brought about by changes to diet alone.
Using this, we can ask important questions, such as:

- Are there any differences when mice are fed a high fat diet for a short period vs. a longer period of time?

- Can damage to the photoreceptors ‘spread’ to other parts of the eye?

- What will happen if we increase or decrease the dietary fat content of these mice?

- Can damage due to unhealthy foods be reversed through a better diet?

Answers to these kind of questions will help us better understand how diet can affect a person’s chance of developing AMD, why disease may first develop in certain parts of the eye and at what rate it progresses.

They will also help to inform dietary advice for those wanting to reduce their risk of developing AMD.

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**Take your marks!**

We have fundraising places in some of the UK’s top 2017 runs, so why not get involved, or encourage family or friends to sign up?

- Edinburgh Marathon Festival (all distances) – 27/28 May
- Great Manchester 10k – 28 May
- British London 10k – 9 July
- Great North Run, Half Marathon – 10 September

For more information: www.macularsociety.org/runs or contact Kathy on 01264 321 964 or kathy.k@macularsociety.org

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**Helpline** Our helpline staff are friendly and knowledgeable professionals who can answer questions, and provide information and advice about any aspect of living with macular disease.

0300 3030 111  Mon to Fri 9am to 5pm  help@macularsociety.org
Jackie’s wish

Jackie Brown is passionate about research. She takes a keen interest in the progress being made, but knows that more funds are needed to find a cure. So Jackie has chosen to leave a gift in her Will to the Macular Society.

Jackie hadn’t heard of age-related macular degeneration (AMD) until she was diagnosed. Seeing strange wavy lines just a day before her holiday, she contacted her GP, then Specsavers. The quick thinking staff got her an appointment at Redhill eye clinic just one week later, on her return from Egypt. “I couldn’t fault that”, she says.

Getting to the clinic however was complicated, involving three changes of bus and train. So Jackie joined the campaign for a local clinic. One duly opened in Horsham and although her treatment still takes place at Redhill, it makes pre-treatment check ups easier.

Jackie knows that AMD treatment is available thanks to ongoing investment in macular research. “Sight is so precious”, she says. “We should be doing everything we can to protect it and find a cure for conditions that threaten it. I’d encourage anyone to consider leaving something in their Will to help the Society fight AMD.”

Many of you, like Jackie, have remembered the Society in your Will. Your gifts are as important as ever. If you have, thank you so much. One in three helpline calls and around a third of our research is possible because someone, many years ago, remembered the Society.

For more information or wording to add the Macular Society to your Will go to www.macularsociety.org/legacies or call Caroline on 01264 321 988.
Trekfest the Peaks

Our Helpline operator, Jane McFarlane, has certainly gone that extra mile to fundraise for us!

Jane, her husband Billy and friends Tina and John Guyatt, challenged themselves to the Trekfest 25k sponsored hike in The Peak District, raising almost £2,000.

Despite torrential rain throughout, Jane’s ‘MacLas’ team completed their challenge in six hours, finishing an impressive 85th out of 282.

Jane said: “It was such a well organised event with a great atmosphere. Although the wet weather was persistent, we managed to keep our sense of humour; albeit feeling drenched by the end of the challenge!”

Their sponsorship is being divided between the Society and Andover Life After Stroke. A massive thank you to Jane and her team!

Left to right: Tina Guyatt, Billy McFarlane, Jane McFarlane and John Guyatt celebrate completing their Trekfest challenge.
Turning it around – how volunteering changed my life

Since becoming a volunteer for the Society, learning more about macular disease, educating others and helping those affected has become Barbara Hogg’s passion.

The 93 year old, who has trained as a speaker, a Skills for seeing trainer and a telephone befriender, lost the central vision in her left eye in 1993. But her vision loss did not truly affect her until she developed wet age-related macular degeneration (AMD) in her right eye 13 years later.

She admits feeling very isolated. “I felt quite suicidal and I’m not ashamed to say that,” she said.

“I couldn’t expect help from my older brother, but my younger brother did his best, taking me to my injections. I had no children, I felt completely alone.”
Shortly after her diagnosis, Barbara was inspired to start volunteering after hearing an interview with Terry Pratchett about his diagnosis of Alzheimer’s disease.

She said: “Terry said we have two choices when you are diagnosed with something you know is going to get progressively worse. You can either sit back and let it happen or you turn it around and do something constructive. So, I turned it around.”

She added: “Volunteering for the Macular Society has changed my life, because it saved me giving up and ending up in a home. I don’t have as much energy as I would like, but I can still get on a tube and travel, and I still do the things I want to.”

In her role as a speaker, Barbara regularly visits City University to talk to optometry students, raising awareness of macular disease as well as Charles Bonnet Syndrome visual hallucinations. Having previously worked as a teacher and later a teacher trainer, she said: “I really enjoy speaking to students and teaching them about macular disease through my own experience.”

Barbara also visits local groups and societies to raise awareness of the condition, and offers support and advice to people on an individual basis.

She also ensures she stays up to date with the latest research. She added: “It has become my passion. I want to help people because I have been through it, and am still going through it.

“We have come a long way and we know much more about AMD now. I’m quite positive about it now. There are problems still – everywhere you go you have to make compromises, but you learn to accept it.”

Earlier this year Barbara received an award from her local mayor in Barnett for her support in the local community.

If you would like information about volunteering for the Macular Society please contact the volunteering team on 01264 326 622 or email volunteer@macularsociety.org
“Waltz with a twist” was the intriguing title of a ladies’ golf day, which has helped raise vital funds and awareness.

Organised by Di Daniels, Ladies Captain at Barnham Broom Golf Club in Norfolk, the day involved golfers taking it in turns to play a hole wearing Sim Specs. These give wearers an impression of what life is like living with late-stage macular degeneration.

The event was part of a year-long series of fundraising activities, after Di nominated the Macular Society as one of her chosen charities. She explained: “As Lady Captain, I chose the Macular Society and Blind Veterans as my charities for the year, as my husband has age-related macular degeneration and has been helped by both. All the fun competitions I have run have raised money from the contributions of my generous ladies.”

And members of Durham Central Ladies Bowling League raised a fantastic £1,220 towards our research fund, after nominating us as their summer season charity beneficiary.

Joyce Woodward, the League’s Honorary President said: “There were a number of reasons for choosing the Society, not least being that some of our members suffer from the condition. We are proud to say that they continue to bowl using aids – reflective sticks and anti-glare glasses – and, with help from other players, are very successful.”

A huge thank you to all our charity of the year fundraisers! If you belong to an organisation that fundraises for charity, please consider nominating the Society.

For more details, contact Kathy on 01264 321 964 or email kathy.k@macularsociety.org
Local spotlight
on Sarah Burchett and the Guernsey Support Group

An optician in Guernsey has been praised for her commitment to her local macular support group.

Sarah Burchett, from Specsavers, is a regular attendee at the island’s group, taking part in discussions and talking one on one with members about their concerns.

Sarah also fundraises for the group and helps to promote the Society and the meetings, from her high street branch.

Some of the activities include raising awareness of the Society in the branch’s newsletters, incorporating a ‘Quote of the Month’ from the Society, making sure patients are aware of the group and putting up promotional posters in store.

She first got involved with the group last year after meeting group leader Bill Gardiner at a review meeting about the ophthalmology services on the island.

Sarah Burchett (far right) and her team at Specsavers, Guernsey
Bill runs the group along with Tilly Fisken. Sarah got in touch with them following the meeting and decided to go along to the group.

She said: “The group, under Bill and Tilly’s leadership, are exceptionally upbeat and positively determined to get on with their lives, despite their conditions.” She added: “It was also clear that from the branch we had a direct opportunity to ensure we promoted and supported patients to get involved with the Society, and raise awareness.

“Also, having funds is a positive for any group as it allows flexibility in supporting members with social events, without the members worrying about having to financially contribute themselves, particularly as many people are on low incomes.”

This year, Sarah was nominated and went on to win ‘Optician of the Year’ in the Society’s annual Awards for Excellence, for her dedication to the group. She said: “I love attending the meetings. It’s a fun and engaged group with monthly speakers and a social event. It has been such a pleasure and very inspirational working with them.”

Bill, who nominated Sarah for the award, said: “Sarah has been an almost ever-present member of our group. She is very dedicated to being there every month and she is always cheerful, informative and enthusiastic. She is also very knowledgeable and can talk about all of the conditions from a specialist point of view, and often answers questions.”

He added: “Sarah has also raised money for the group and has become a steadfast supporter of everything we do. It is her level of commitment which is quite unique.”
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