

Autumn 2021 Issue 137

# Sideview

For members of the Macular Society

## Cheering you on

Support for your  
body and mind

## Inside this issue

- Adapting to the new normal
- Thanks to you, research is back
- Top cooking and makeup tips

  
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Beating Macular Disease



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## Sideview

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**Front cover:**  
Suzanne and David's 100-mile trek (page 34)

# Welcome to autumn Sideview

Cecilia Bufton, Chair



Over the last 18 months, it may have felt like time was standing still. None of us is quite the same person we were in March 2020 – whether that’s down to the coronavirus pandemic, or something else entirely.

Perhaps you’re a little less flexible than you were. Maybe you’ve taken up a new hobby, or had more time to practise it at home. You might be feeling more fearful or reluctant to take risks, especially if your sight has deteriorated.

Some people will undoubtedly have leapt back into their old lives when restrictions were lifted, but many others will need time to adjust.

With this in mind, we’ve collected advice and resources to help all our members look after their bodies and minds – whether that’s regaining your confidence (page 28), getting the most from virtual medical appointments (page 24) or even perfecting your makeup (page 38).

One thing that is up and running at full steam is our research programme. We introduce four of the projects you’re getting off the ground in 2021 on page 12.

Thank you as ever for all your support, and enjoy Sideview.

**Cecilia Bufton**  
Chair





Macular Disease Conference 2021  
**Hope for the future**

## This year's Macular Disease Conference, on 11 September, was bigger than ever

Thousands of people virtually joined our talks on the latest research, tailored support and practical advice, and had their questions answered live by experts in the field.

And if you missed out, there's plenty of time to catch up online in your own time.

**The inherited retinal diseases and working-age session** covered genetic testing, developments in the treatment of diabetic eye disease, a possible treatment for Stargardt disease and a session on physical

and mental health hosted by British Blind Sport and our patron, Paralympic sprinter Zac Shaw.

For people with **age-related macular degeneration (AMD)**, experts discussed stem cells, what we can learn from eye scans, what exactly goes wrong in eye cells during AMD, and new treatments that could make it into clinics in the next few years.

And this year, for the first time, we held a separate, back-to-basics session for people newly diagnosed with macular disease, and their friends and family.



Kindly supported by



The **‘Macular and Me’** stream covered a beginner’s guide to the macula, information about the emotional impact that macular disease can have, and an introduction to peer support and practical tools to make life easier.

**Watch all the sessions online at**

**[macularsociety.org/conference2021](https://macularsociety.org/conference2021)**

**There’s no need to register, pay, or download anything – all you need is a computer or tablet with an internet connection.**

## **New member? Welcome!**

If this is your first Sideview, you might be feeling like a rabbit in the headlights, especially if you’re new to macular disease. So if nothing else, keep hold of these numbers.

- **Questions about your membership?**

01264 350 551 or  
[supportercare@macularsociety.org](mailto:supportercare@macularsociety.org)

- **Questions about your treatment, condition, or ways the Macular Society can help you?**

0300 3030 111 or  
[help@macularsociety.org](mailto:help@macularsociety.org)

And out of office hours, there’s a wealth of information about macular disease, looking after your eyes, and living well with sight loss on our website at [macularsociety.org](https://macularsociety.org)

**Thank you for joining us, and welcome to our community. Together we will Beat Macular Disease.**



**Professor  
Majlindo Lako**  
Newcastle University

## From the conference: Leaky rubbish bags and disease messengers

The human body contains many different types of cell, each with its own distinct features and structure. A blood cell looks very different from a skin or nerve cell, for example. But stem cells have the potential to change into more than one type of cell, and that makes them extremely useful in research.

We can now take stem cells from adult patients, and use them to

create cells and tissues that are usually very hard to observe – like the RPE cells at the back of the eye, which are the first to be affected by age-related macular degeneration (AMD). That means that we can test new treatments on cells that are genetically identical to those in the eye of someone with AMD, with no risk to the patient.

### Inside the cell

Using this technique, we compared the RPE cells of people with and without AMD. The cells with AMD were more stressed and more inflamed. We saw more built-up fat and drusen deposits, and the cells' mitochondria (energy sources) were different



too: fewer and larger than those in healthy RPE cells.

We also saw that waste inside the cells wasn't being disposed of properly – the 'bags' that usually swallow up waste, called lysosomes, were swollen and leaky, so rubbish built up inside the eye and caused damage to the eye cells.

## Cell messengers

Another side effect of this build-up is an increase in the number of exosomes being released. These tiny bubble-like structures travel between cells all the time to help repair damaged tissues, grow new blood vessels and encourage

blood to clot around an injury. Incidentally, viruses can also use exosomes to spread from one cell to another.

Exosomes from cells with AMD look different from those leaving healthy cells, and when they reached an otherwise healthy 'control' cell, we observed some very familiar inflammation and cell stress – the same type we'd expect to see in AMD cells. In other words, exosomes were acting as disease 'messengers', spreading the AMD symptoms and causing a chain reaction.

If we can improve RPE cells' waste-disposal process, it could prevent not only the buildup of damaging waste materials, but also the spread of inflammation to other unaffected cells. And spotting exosomes with the hallmarks of AMD could help us diagnose it earlier, before a patient notices any change to their vision.

**Watch Professor Lako's full talk at [macularsociety.org/conference2021](https://macularsociety.org/conference2021)**

### Damaged maculas “could be rebuilt”

Research from the London Project to Cure Blindness suggests that people whose maculas are damaged by age-related or myopic macular disease could have their sight restored.



In a talk for the Macular Society, **Professor Pete Coffey** explained: “If you think of the back of an eye like layers of

an onion – you’ve got three layers. The top part, the neural retina, contains all the cells that are sensitive to light. The middle layer, the RPE, is crucial to keeping that top part healthy. Then there’s the blood supply that gives nutrients to both other layers.”

Advances in technology mean that as well as creating replacement light-sensing and RPE cells, researchers can now create the network of blood vessels needed to keep them

healthy – in effect, a light-sensitive retina in a dish.

Professor Coffey’s previous research aimed to treat people with age-related macular degeneration (AMD) but could also help the growing number of people with macular disease caused by severe short-sightedness (myopia).

He continued: “We are now close to being able to seriously think about rebuilding a macula, but there’s still a fair bit of pre-clinical work to be done. It’s not just a case of funding trials – there’s still science to be done to get to the stage where we feel confident that it’s safe and will have some impact.”

## “90 per cent of AMD risk in one of two genes”



Age-related macular degeneration (AMD) is in fact two separate diseases, each driven by a mutation on a

different chromosome, according to **Professor Gregory Hageman** from the University of Utah.

Speaking as part of the Macular Society’s programme of virtual clinics, he laid out research suggesting that 95 per cent of people with AMD had mutations on either chromosome 1 or 10. Although both eventually led to the death of retinal pigment epithelial (RPE) cells, and loss of sight, the process leading to that point was different depending on where the mutation was located.

Patients whose AMD was driven by mutations on chromosome 1 had different patterns of drusen, different retinal thickness, and were more likely to develop dry AMD than those with a chromosome 10 mutation.

Professor Hageman went on to explain how gene therapy could reverse the effects of a chromosome 1 mutation, and to suggest that treatments developed for AMD could be effective for many other diseases affecting the rest of the body: “These chromosomes, and these mutations, exist in cells throughout your body – it would be naïve to think that they only cause disease in the eye. The good news is that any treatments developed to treat AMD caused by mutations to chromosome 1 and 10 should help treat these other diseases too.”

See Professor Hageman and Professor Coffey’s full talks at [macularsociety.org/virtualclinics](https://macularsociety.org/virtualclinics) and register for more of our virtual clinics, held on the third Tuesday, and last Thursday of each month.

We are extremely grateful to The Linbury Trust for their generous grant funding which has helped us to run these virtual clinics.



# Spotlight **New research you're funding**

Everything we learn about macular disease brings us closer to beating it for good. And thanks to Macular Society members, seven new research projects will start this year – each one bringing a cure closer, or making life better today. Here are the first four projects that you are making possible in 2021.



## **1** Healthy mitochondria, better sight: stopping early AMD by helping eye cells to use energy better

**Professor Andrew Dick**

University of Bristol



### **The problem**

Cells in the retinal pigment epithelium (RPE) use a lot of energy, so they are vulnerable to the build-up of toxic waste and damage to mitochondria (the cells' energy sources).

This triggers the immune system and causes inflammation, which is even more damaging.

We have discovered that loss of critical molecules including IL-33 disrupts cell metabolism: the way cells use energy. This causes cell ageing and harmful inflammation, of the kind we'd expect to see in age-related macular degeneration (AMD).

### **This project**

We want to use this discovery of key molecules to reset RPE health and stop AMD at its very earliest stages.

We will start by introducing molecules into stressed cells

and using genetic profiling to understand how this treatment could help the RPE to work better.

In the second stage, we will explore how best to deliver these potential therapies, aiming to stop or delay the damaging changes.

### Why is this important?

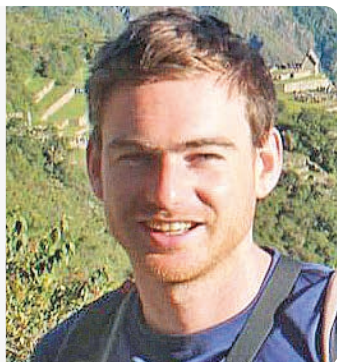
Our project seeks to understand how the immune system and metabolic changes work together to make AMD worse. That understanding could lead to a targeted therapy to treat AMD early, efficiently and safely.

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## 2 METR-GT: The Manchester Eye Tissue Repository Genome-Transcriptome Project

**Dr Jamie Ellingford**

University of Manchester



### The problem

Macular dystrophies (MDs) are genetic conditions that can cause problems with detailed vision from early childhood. Although we know most of the genes that cause MDs, many individuals do not have a diagnosis, even after extensive genetic testing.

### This project

We will use donated human tissue from the METR to identify common and rare gene changes that impact the expression of genes in the retina – whether the genes are ‘switched on’ or not, and how active they are.

### Why is this important?

One immediate benefit will be improved interpretation of gene changes that sometimes cause (and sometimes do not cause) MD. This will mean more people get a genetic diagnosis, and are able to manage their condition better.

Understanding how MDs develop and progress could also suggest new ways to treat them.

## **3** Could a flower compound stop leaky blood vessels growing?

**Professor  
Dulcie  
Mulholland**

University  
of Surrey



### **The problem**

Existing drugs for wet age-related macular degeneration (AMD) do not work in all patients, are expensive, and must be injected directly into the eye. Compounds called homoisoflavonoids have the potential to stop abnormal blood vessel growth and prevent sight being lost. However, these compounds are scarce, often come from endangered plant species (including the Hyacinthaceae) and are difficult to isolate in large amounts.

### **This project**

We will be creating a library of homoisoflavonoids and working

through them methodically: testing each one's ability to stop the growth of blood vessel cells, and checking that they are non-toxic.

We will test the most promising chemicals in mice, and examine which targets these chemicals interact with inside the cell. This will give us the information we need to develop one or more homoisoflavonoid derivatives.



### **Why is this important?**

The small molecules that we are developing can be produced cheaply, and could be given as eyedrops or even tablets. This would be a huge advantage to wet AMD patients worldwide, especially in places where it's harder to store and inject drugs safely. Our molecules could be useful for patients who do not respond to the existing treatments.

## 4 Real-life costs and benefits of wearable low vision aids

**Dr Keziah Latham**

Anglia Ruskin University



### The problem

We know that low vision aids (LVAs) help people undertake daily tasks and maintain their independence. And new head-mounted electronic LVAs could supplement or even replace conventional LVAs such as optical magnifiers.

But when members of the Macular Society asked us: “Do you think these devices would work for me?” or “Which of these systems would you recommend?” we didn’t have the independent evidence to answer accurately.

Wearables do improve the ability to read letters on a test chart. However, how helpful they are

when performing everyday tasks, whether they affect a person’s quality of life, and whether they are cost-effective is not yet clear.

### This study

We will recruit 42 people with macular disease and place them in three groups. The first group will receive standard low vision care including optical LVAs.

The second will receive standard care and an iPod with apps for visually impaired people. The third will receive standard care and a wearable device.

After three months, we will compare the devices in terms of their use, impact on quality of life and cost-effectiveness.

### Why is this important?

If these devices are a cost-effective way to improve quality of life, a case can be made for them to be funded and provided in NHS low vision clinics.

Find out more at [macularsociety.org/research](https://www.macularsociety.org/research)

# The story behind the data: AMD and the UK Biobank

**Professor Paul Foster, UCL  
Institute of Ophthalmology**

**Professor Tunde Peto,  
Queen's University Belfast**



## The problem

Age-related macular degeneration (AMD) is the biggest cause of sight loss in the UK, but it's often not spotted until a patient's sight has been irreparably damaged.

We know that both genetics and environmental or lifestyle factors can affect whether someone develops AMD and how quickly it develops. Understanding more about how nature and nurture affect someone's risk could help us advise people better, and

develop new treatments tailored to their specific genetic makeup.

## This study

We used data from the UK Biobank: a huge database of anonymised medical and lifestyle information collected from half a million volunteers between the ages of 40 and 69. This data includes photographs of the retina's surface, and cross-sectional imaging that shows each of the layers within it, for almost 69,000 people.



We worked with a team of trained experts to examine every one of these images, looking for the early signs of AMD including yellow deposits called drusen. Around nine per cent of the images showed some early signs.

We'll examine the other test results and medical information the Biobank holds about these people to understand if they have particular genetic variants or lifestyle factors in common. And over the next few years, we'll keep track of whether they go on to develop AMD, what type, and at what rate.

### What next?

We estimate that by 2023, 1,800 of the UK Biobank participants whose eye images we examined will have developed either wet or dry AMD. Our analysis and grading of their initial images gives us an incredible opportunity to work out

which warning signs are most likely to lead to sight loss, and which eye specialists should look out for.

Understanding the different types of AMD also means we can give patients a better idea of how much of their sight they are likely to lose, and how quickly. And it means that in the future, other teams of researchers can use our data to better understand how AMD develops, and create targeted treatments to stop it in its tracks.

**Research like this is Beating Macular Disease, and it couldn't happen without your support.**

Thank you for giving researchers like these the resources to solve some of macular disease's biggest mysteries, and bring us all closer to a cure.



# News

## ▶ Beovu® “gives us a new treatment option for wet AMD”

**Professor Faruque Ghanchi** answered questions from Macular Society members during a virtual clinic about the newest drug treatment for wet age-related macular degeneration (AMD), brolucizumab (known as Beovu®) in June 2021.

The consultant ophthalmologist at Bradford Teaching Hospitals and national vice-chair of National Institute for Health Research explained that studies showed Beovu was just as good as existing treatments at slowing sight loss caused by wet AMD. For many people, the effects of Beovu lasted longer, so fewer injections could be given.

He went on to say: “At the moment, most clinicians are using Beovu only when the other three treatment options aren’t providing optimum control of macular degeneration.” Whether it’s recommended will depend

on how well existing treatments are working, the condition of a patient’s other eye, and the structure of the macula.

Professor Ghanchi also stressed that eye specialists would continue to refine the treatment. He said: “So far, Beovu is a very useful additional treatment option, but it’s not yet the game-changer that we are all looking for.”

Listen to Professor Ghanchi’s presentation at [macularsociety.org/virtualclinics](https://macularsociety.org/virtualclinics)



▶ **Video: Professor Faruque Ghanchi discusses the new treatment for wet AMD, Beovu®**



## ▶ More than nine in ten “would recommend the Macular Society”

Three-quarters of people say that contact with the Macular Society had improved their situation, a survey found. In early 2021 we surveyed 300 people who had used one or more of our services.



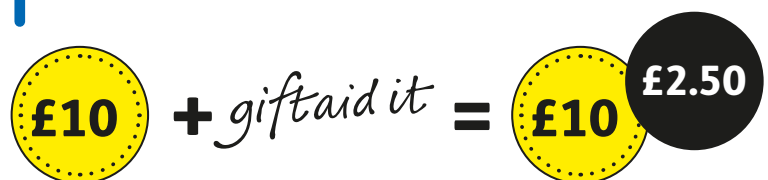
More than nine in ten said that they trusted the Macular Society to provide them with the right information, and a similar number would recommend the Society to other people. And almost seven in ten said that contact with the Macular Society had given them the confidence to live life as they want to.

Thank you for being there for people who need us. Your kind support means we are Beating Macular Disease together, every day.

## ▶ Two easy ways to Beat Macular Disease

Did you know that if you are registered as sight impaired or severely sight impaired, Royal Mail allows us to send Sideview and other publications to you for free? The **Articles for the Blind** scheme saves the Society thousands of pounds a year, but we need your permission to use it.

If you are a UK taxpayer, please let us know that we can claim Gift Aid on your kind donations. For every £1 you donate, the Macular Society can claim 25p from the UK government. You can also let us know if you are no longer eligible to make a Gift Aid declaration.



Update your Gift Aid or Articles for the Blind preferences by calling 01264 350 551 or emailing [info@macularsociety.org](mailto:info@macularsociety.org)

# Past memories, future hopes

## “We have found it so rewarding”

Raising funds in memory of a loved one is an inspiring way to Beat Macular Disease, as the Radia and Dattani families have shown. Together they have raised an awesome £4,310 through their Step Around the World challenge, in memory of their much-loved dad, grandad and uncle, Dhirajlal Devi Thakrar, known as Dhirubhai.

Nimisha Radia says: “Our beloved dad sadly passed away in 2020. He was a kind, generous and warm man who loved to laugh and was always full of energy.

“In his last years, life became more challenging for him with age-related macular degeneration (AMD).

“As his eyesight slowly deteriorated, his confidence took a massive drop and all the things he enjoyed, such as watching cricket, reading and eventually driving became non-existent.

“In memory of our wonderful dad, we wanted to help with research and support others who might be suffering like dad did. We have found it so rewarding to

do the step challenge and are so grateful to everyone who supported us.”



The Radia and Dattani families step out to Beat Macular Disease

## “Your eyesight is precious. Mom was precious too”

Our online tribute pages make it easy for family and friends to sponsor your challenge. But if stepping out is not your cup of tea, a tribute can also be a quiet place to remember and celebrate the life of someone you love, while giving to Beat Macular Disease in their memory.

Tracy Hughes has a tribute page for her mother Irene who had dry AMD and other health issues. She was fine indoors, but became afraid to go outside, gripping Tracy’s arm tightly as she was scared of falling. But Irene didn’t let this get her down. She had a ready smile for everyone, even when she couldn’t see them well.

Irene enjoyed her new life in Devon, where she moved in 2001 with Tracy’s family. “Mom loved taking her beloved grandsons down to the beach and spending money on them in the little gift shops,” says Tracy. “She used to say ‘Look



Irene with grandsons Craig and Dean



after your eyesight, it is a precious thing’. Mom was precious too.

“My boys and I miss her but the love we have for her and our wonderful memories will stay in our hearts and minds forever. Mom had six daughters and we will keep donating to her page on birthdays, Christmas and Mother’s Day. We are glad that our donations will make a difference and help others. She’d have liked that.”

To donate, create a tribute, or fundraise in memory visit [macularsociety.org/inmemory](https://macularsociety.org/inmemory), email [inmemory@macularsociety.org](mailto:inmemory@macularsociety.org) or call Debbie, Corinne or Kathy on 01264 560 222.

# Over to you . . .

This Macular Week, our members took the spotlight



When it comes to raising awareness of macular disease and encouraging people to look after their sight, it's not scientific diagrams or dry statistics that make the difference. Our members' stories are the most powerful tools we have, and during Macular Week they're more vital than ever.



## Nic's story

In summer's Sideview, we introduced Macular Society member and teacher Nic Spearman, who has Stargardt disease. Her story, and our members' support in sharing it far and wide, meant that our dedicated Supporter Care team answered more than 200 calls on the Wednesday of Macular Week. And in the first four days, more than 1,000 people made a donation to Beat Macular Disease sooner, for Nic and everyone like her.

“I worry about what my son might miss out on as a result of my sight loss. I strongly believe that because of my condition, he will grow into a caring, compassionate, resilient and independent person.

But I do worry about helping him with reading, writing, homework, and creativity. I'm afraid I won't be able to support him the way I feel I should do, as his mum.”

## Daily life with Leanne and Chris

Over on our Instagram channel, Leanne Harvey (@learningtoloveanne) and Chris Owens (@blind\_man\_with\_a\_backpack) shared their everyday realities and brought macular disease alive for people who might never have heard of it before.



Their photos and short video clips showed the challenges of commuting with sight loss, the daily combination of

medication that Leanne takes to keep her punctate inner choroidopathy (PIC) under control (see page 42) and how their treatment and lives have been changed by the pandemic.

## In your own words

We asked our members and supporters: “What would a cure mean to you?” Their answers do more than anything else to explain why we must **Beat Macular Disease:**

- “I wouldn’t have to worry about my husband’s eyesight deteriorating further.”
- “Not having to worry about all the things I will never see if I lose my sight.”
- “The chance to see my grandchildren grow. To be able to read to them.”
- “Hope for future generations.”
- “Freedom.”
- “Everything.”

## Ready to share your story?

Email [stories@macularsociety.org](mailto:stories@macularsociety.org) or join the macular community on Facebook, Instagram or Twitter [@macularsociety](https://www.instagram.com/macularsociety)

Dozens of our hardy supporters took on personal step challenges as part of Step Around the World (from home), clocking up the miles while raising money to **Beat Macular Disease**. Whether you walked, ran or cycled (or sponsored someone else to!) you’re part of the team bringing an end to macular disease closer for all of us. **Thank you!**



# The new normal

Taking health consultations ‘virtual’ is keeping patients safer and saving everyone money and time. But it can also bring extra stress, especially for people with sight loss. The Macular Society brings patients and professionals together to make sure that these digital solutions work for everyone.

## Advice for patients

“Before the pandemic, we would never have thought you could run a low vision clinic over the phone,” says



**Moyra McClure**, a specialist optometrist based in the Belfast Trust, “but we had to do something.”

The NHS low vision service still can't see as many patients in person as before, but has had surprising success running low vision consultations over the phone. Moyra gives a few examples: “We talk through people's concerns and send out magnifiers, glare protectors and information leaflets through the post. We also take time to talk through the

emotional aspects, and find out whether the person has been having visual hallucinations.”

Having a consultation from home has brought other advantages too. “Some people really open up more over the phone, and are more likely to consider telephone counselling if they're struggling. And it can be easier to tell whether something's working if you're in a familiar environment, not stressed about being somewhere new or how you're getting home.”

The important thing for low vision care is to treat each patient as an individual, and address the concerns they have. Moyra explains: “Everyone is different – some are most worried about being able to cook like they used to, but for others it's



watching TV, reading their newspaper or using the phone.”

Although low vision services vary across the UK, there’s a supportive network of specialists and charities including the Macular Society working to find the right solution for each person.

### **Moyra’s consultation tips**

- Before your appointment, think about the practical problems you’d like to solve. What tasks are you finding most difficult, or do you most miss doing for yourself?

- The more information we have about your eyesight, the more specific we can be with our help. If you haven’t had your eyes tested recently, or don’t know your level of sight on the letter chart, think about the size of print you’re able to read.
- Even if we can’t help directly with something, we can recommend other services like telephone counselling or the local sensory support team. So if that’s something you want to know more about, ask us!

▶▶ continued



## Advice for professionals

The Northern Health and Social Care (HSC) Trust asked different groups, including local Macular Society support groups, about the benefits and pitfalls of telephone or video consultations.

Senior regional manager Karen Toogood explains: “Members who had had virtual consultations were pleased to avoid going into hospital if they didn’t have to, especially during the height of coronavirus. And others were relieved not to have to worry about getting public transport to a physical appointment.”

But members were also worried about taking in all the information they were given without another person present, especially if it was bad news. And there were practical considerations too – one member recalled being unable to tell their consultant their weight as they couldn’t see to read the scales.

From their discussion, the group put together this list of recommendations for the HSC Trust.

- Help people prepare for a virtual consultation by sending

accessible information beforehand about who will call, how long it will last, and any information they will need to have ready.

- Invite patients to think about whether they’d like someone to be with them during the call.



- Speak clearly and encourage patients to take time to ask and answer any questions.

**Your support is keeping groups like these running, and ensuring that the voices of people with macular disease are heard where it matters. Whatever changes lie ahead, we will navigate them together. And together, we will **Beat Macular Disease.****

# Regaining your confidence



If you're finding it hard to 'snap back' to your pre-coronavirus life, you're certainly not alone. Here are our tips on finding your way to the new normal.

## Out and about

A lot can change in 18 months, so if you haven't left the house for a long time, it might be a good idea to re-familiarise yourself with old routes you used to walk, perhaps with a family member or friend.

And if you're worried about catching public transport, shopping or eating at a restaurant, find our tips at [macularsociety.org/getting-around](https://macularsociety.org/getting-around)



## Exercise

A lot of us have been less active recently, with knock-on effects on our flexibility, stamina and balance. Ease yourself back into exercise with some at-home workouts specifically designed for people with sight loss.

- ▶ Find audio-only workouts, from chair yoga to interval training, by searching [youtube.com](https://youtube.com) for 'eyes free fitness'.
- ▶ British Blind Sport has collected several sets of accessible workouts at [britishblindsport.org.uk/active-at-home](https://britishblindsport.org.uk/active-at-home)
- ▶ Move it or Lose it workouts focus on simple ways to maintain your strength, flexibility and balance. You can order a CD or series of DVDs from [moveitorloseit.co.uk](https://moveitorloseit.co.uk) or by calling 0800 612 0450.



- ▶ 10 Today is a series of 10-minute audio-only workouts. Find the full back catalogue at **10today.co.uk** or listen live on local community radio each weekday – there’s a full list of stations on the website.

## It’s good to talk

The last eighteen months have been profoundly isolating. If you’re ready to make some new friends who understand life with macular disease (even if that’s not all you talk about) we can help.

- ▶ Find a Macular Society support group near you, whether it meets in real life, virtually or a little of both, at **macularsociety.org/groups** or by calling the Advice and Information Service on 0300 3030 111.
- ▶ Call the same number if you’re interested in regular calls from a befriender, or would like to be referred to one of our trained telephone counsellors.
- ▶ And if you’re worried about going back into the office, we can connect you with someone in a similar career to share tips and advice – email **colin.daniels@macularsociety.org**

## Make the most of your vision

You might feel that your sight has deteriorated, especially if you’ve missed appointments or your treatment has been delayed.

- ▶ Find our tips on lighting, technology and driving at **macularsociety.org/resources** or call 0300 3030 111 to ask for a large-print paper copy.
- ▶ Speak to your consultant (or GP) about being referred to a low-vision clinic, or registering as sight impaired or severely sight impaired.
- ▶ Our Connect by Tech volunteers can help you get the most out of tablet computers, e-readers, home assistants and smartphones. Call the Advice and Information Service or email **techtalk@macularsociety.org**



**Your support over the last eighteen months has been more valuable than ever. Thank you for being there for people with macular disease, and for making sure people don’t have to face the challenges of sight loss alone.**

# Wear yellow for George

In winter 2020's Sideview, we introduced you to seven-year-old George, who has Stargardt disease – an inherited macular condition that can affect even young children.

Almost a year on, and although George's eyesight has deteriorated further, he is adapting brilliantly. His school, Great Binfields Primary in Basingstoke, is helping him to learn Braille and touch-typing.

And in June 2021 the whole school joined together to raise more than £400 for the Macular Society by holding a 'Wear Yellow' non-uniform day, and a raffle of yellow items.

## Outstanding support


George's mum Sarah says: "George has been doing so well with his Braille and touch-typing. Lockdown was very tricky as I didn't know Braille at all and part of his home learning was Braille. Thankfully George has managed to catch up since he has been back in school. He already knows the Braille alphabet and is phenomenal on the Perkins Braille which we tracked down on eBay, of all places!"

Sarah has nothing but praise for the support George's school has offered: "They have been outstanding with helping him on his journey. We asked them to share the video of George that was filmed for the Macular Society and they came up with the idea to do a specific fundraising day."

## Keep on smiling

One of the most difficult parts of the last year has been not being able to see other members of the family, including Sarah's mum Carol, who lives in Leeds.

Sarah says: "Thankfully we can now see family again. My mother hadn't seen him in a year, and she really noticed the difference in George's vision. But his can-do attitude has remained unscathed and he continues to approach everything with a smile on his face."



“I am really enjoying learning Braille and also the keyboard. I really enjoyed our Macular Society day at school. It is important to try and raise lots of money to find a cure!” – George, 8

Want to organise your own Wear Yellow day at school or work?

Give Susie a call on 01264 560 249 or email [community@macularsociety.org](mailto:community@macularsociety.org) – we’d love to help, and of course see your photos!

And if you or someone in your family has an inherited macular condition like George, you’ll find support, advice and understanding on our dedicated Facebook group. Just search [facebook.com](https://www.facebook.com) for ‘working age and young people’s group’.



# You don't have to talk about your eyes all the time!

Macular Society member Carol Yates can remember exactly the moment, 15 years ago, when she realised something wasn't right with her eyes. "I didn't have my glasses on, and I was looking at a couple of picture frames in my room, and the corners were funny," she recalls.

"I went to the optician the next day and in no time I found myself at the hospital. The night before, I hurried to the end of the book I was reading. I remember thinking: 'I've got to finish that book tonight, just in case I don't get a chance.'"

Eventually Carol was diagnosed with wet age-related macular degeneration (AMD) in her left eye, as well as the glaucoma that affects much of her family.

## ► Today and tomorrow

After discovering the Macular Society, she became a member and enthusiastic supporter of research. Carol says: "If in so many years' time my children or grandchildren were diagnosed with macular disease, it would be almost as though time had stood still. We do need new research, and to find new treatments. But knowing that I'm not the only one with this condition also helps, in a way."

It's that sense of community that led Carol to volunteer as a befriender in 2014. She says: "When I joined the Macular Society, I didn't know anything about macular disease at all, so it was quite reassuring to feel

that, if I did have any queries, I had somebody to ask. And so I thought, 'I've got plenty of time. Why don't I help somebody not medically, but socially?'"

In seven years of regular calls, a few themes have emerged. "I very rarely talk about the medical side of things," Carol admits. "If somebody asks me, I can say a little bit, but I prefer more of a chat about everything. Just because you've got macular disease, you don't have to talk about your eyes all of the time!"

### ► You're never alone

So what makes a good befriender? First, being a good listener, as well as a good talker. "I can chat for England!" Carol smiles, "but I can also listen. I think it's best if you can use your own experiences to help you relate to somebody, but also

to remember that the person you're talking to is the one with the problem.

"If I were the only one, that would be very hard to deal with, but it helps knowing that there is a whole society of people out there that I can talk to."



**Demand for telephone befrienders has soared over the last year. Could you be a friendly voice and listening ear like Carol?**

Find out more about the role, and apply at [macularsociety.org/beafriend](https://macularsociety.org/beafriend) Or perhaps you'd like regular calls from someone who understands life with macular disease? **Call 0300 3030 111 to register your interest.**



# Walking the talk

“Before I started working for the Macular Society, I took my vision for granted: I think many of us do,” says counselling co-ordinator Suzanne Roberts. “When I went for an eye test, I never considered that there would ever be a problem that my contact lenses or glasses couldn’t correct.”

But more than ten years of counselling people with sight loss has changed Suzanne’s perspective. “I have listened to hundreds of people describe the

massive emotional and physical impact of being diagnosed with a visual impairment,” she reflects. “Now, when I go for an eye test, I feel very fortunate when I am told my eyes are healthy.”

That’s why Suzanne and her husband David took on the 100-mile challenge of the South Coast trek. Setting off from Winchester, they arrived in Eastbourne, footsore and weary, eight days later.

“Our appeal is to everyone, whether personally affected or otherwise, to beat the devastation caused by macular disease, and for us all to look after our eyes,” Suzanne explains. And her efforts have certainly paid off – she and David smashed their original £1,000 fundraising target before they’d even pulled their boots on, and their current total stands at a brilliant £1,721.

“The whole walk was a wonderful experience, apart from the shock of the naked ramblers! We saw some fantastic wildlife and met some great people,” says Suzanne.



They'd also planned a treat at the finish line to keep them motivated: "We booked a nice hotel for our final evening, so that we could have a well-earned rest and a glass of bubbly before getting the train back to London," she says.



See the latest fundraising total and donate to Beat Macular Disease at [justgiving.com/fundraising/suzanne-roberts17](https://justgiving.com/fundraising/suzanne-roberts17)

## Your counselling FAQs

### Why might counselling help?

Losing your vision is a form of loss: many people compare it to a bereavement. You can't bring back the person you were before, but life is not over. It might be different, but life will go on.

### Why speak to a stranger instead of friends or family?

It can be helpful to talk to someone neutral, without any preconceptions about you, or link to you or your family. And our trained counsellors are experts at helping you overcome the specific challenges that sight loss can throw at you.

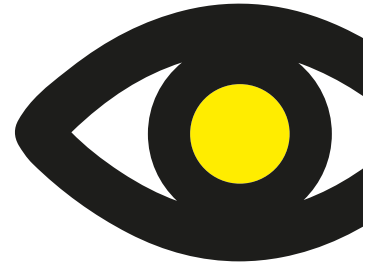
### What's the aim of counselling?

A lot of people with sight loss go through a period of feeling quite low, particularly when they're first diagnosed, or their sight deteriorates. We can't give you back your vision, but we may be able to help you find new ways of coping and thinking about your situation, which can help you to feel more fulfilled, inspired or hopeful.

**Find out more by calling our Advice and Information Service on 0300 3030 111.**

In 2020, 488 people were referred to our telephone counselling service – up from 264 in 2019. Thank you for helping Suzanne and her team of counsellors to be there when people needed them the most.

# Thirty-four years of Beating Macular Disease



Founding member of the Macular Society, retired eye surgeon, and new Society President Tim ffytche reflects how far we've come since the day in 1987 that a very persuasive letter dropped onto his doormat.



The writer was **Elizabeth Thomas** and her opening sentences showed me that she was an exceptional woman; indeed she once described herself as 'an unappropriated blessing'.

She wrote: "First let me introduce myself: I am a single woman of 72 years who in 1983 was registered blind owing to macular degeneration. Through a series of circumstances of which I am not entirely the mistress I have found myself the co-ordinator of a very small number of people suffering from macular degeneration, of all

ages from 8 to late 70s, who would like to have a special group formed for people suffering from this disorder [...].

- To offer each other encouragement and support;
- To circulate amongst ourselves information about low vision aids to enable us to perform our daily duties more successfully;
- To maintain contact with a research unit undertaking research into macular degeneration itself."

## "Nothing we can do"

Sadly back in 1987 ophthalmologists had little to offer patients with macular degeneration. The symptoms were well-known, and it was possible to distinguish the various forms, such as 'wet' and 'dry', using retinal photography and fluorescein angiography.

But, when it came to therapy, there were great limitations. The only positive treatment was

the laser, which was often too damaging to use safely by the time symptoms were noticed. There was no active treatment for dry macular degeneration, and usually all the ophthalmologist could offer was referral to a low vision clinic, sympathy and ultimately registration as partially sighted or blind.

## First steps

I have never discovered why Elizabeth Thomas chose to write me: whatever the reason, I was sufficiently intrigued to agree to meet her and two other members of her group, and not long after to attend the group's first meeting.

It was arranged by **Amresh Chopdar** (Choppie, to his friends) who was a consultant at the East Surrey Hospital, Redhill.



On 3 October 1987, around 100 people filled the hospital's gym to hear Elizabeth's welcome, and talks from Choppie and me.

We all agreed that a national organisation was needed to help people with macular disease. A committee for the Macular Disease Society (now the Macular Society) was set up that day, with Elizabeth elected as its Chairman. Later she became its first President.

The rest, as they say, is history. A lot has changed since then, but the Society still has as its heart the three aims of the patients Elizabeth Thomas collected under her wing: support, information and research. How proud I am that 34 years later I am in a position to make sure that it continues to follow the same path.

**Tim ffytche**



**Thanks to your support, the story today is much brighter for people diagnosed with macular disease.**

Find out more about the ways our macular community is Beating Macular Disease at [macularsociety.org/support](https://macularsociety.org/support)

# Tips for VIPs

## Part XIV: Applying makeup

Whether you save a full face of makeup for special occasions, or don't go as far as the corner shop without your lippy, it can be tricky to apply cosmetics when you have sight loss. Thankfully the members of our macular community have plenty of tricks up their sleeve. Here we share some of their best tips.

### Tools for the job

- A good magnifying makeup mirror with a light is useful. Some mascara goes on it, but you can get up really close and it keeps both your hands free.



- I recommend the Charlotte Tilbury chunky eyeliner pencils. They're so easy to use that I don't even look in the mirror to apply, and you can smudge them but they don't smear all over your face.

- I now use travel-size brushes to apply makeup – they have shorter handles which means you can get right up close to a mirror. Look out for some with full size heads but shorter handles – mine are from Spectrum.



- I switched from brushes to a sponge, as I found it was more forgiving.
- I always take a selfie, post-application: you can zoom right into areas that you can't see fully and be more confident of the detail.



## Cheats and hacks

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- I use a lot of shimmery and soft colours, so that if I mess up it is hardly noticeable.
- Skip wearing mascara and get your eyelashes tinted at a salon. And having your eyebrows shaped and tinted saves a lot of tweezing and filling-in.
- I found that cosmetic tape got stuck to my eyelashes, so now I hold a bank card on my eyelid to put mascara on – it stops me getting any in places it's not supposed to be!



## Trying things a different way

---

- Sometimes it's easier to put on eyeshadow with fingers, rather than a brush.
- Soft, cream eyeshadows which can be 'dabbed' on gently with your ring finger may work. You can feel where you're going and gradually build up the layer of colour, or just put on a 'wash' of colour.
- I wear sunglasses in most daytime situations because of light sensitivity. Special eye makeup is saved for big nights out!



**Thanks to members of the Working-Age and Young People Facebook Group for sharing their tips.**

To join the group, share your own experiences and pick up tips from more than 600 people in the same boat, search [facebook.com](https://www.facebook.com) for 'Working Age and Young People Group'.



# Winter warmers

We all know that a good story, well told, can make the time fly. And the best storytellers can transport you to another time or place entirely. So we're delighted to announce that our Winter Warmers calls, which were such a comfort to so many people between November 2020 and February 2021, will return later this year.

Each Wednesday from 3 November, you can join us for a lighthearted call between 6 and 7pm.

Whether you already have a passion for theatre, music or history, or want to learn something new, there's something on the programme to suit everyone. Expect personal stories, hidden histories and entertaining performances.

Maria Storesund, the Macular Society's head of regions, explains: "Winter is a difficult time for many people, so our aim is to provide members with a bit of escapism."

Thanks to our fascinating speakers, who all kindly give their time for free, the calls will be informal, fun, interactive and even educational at times. We can't wait to get started again!"

To sign up for any of the calls, just contact the Groups Admin team on 01264 560 259. At time of going to press, a few speakers and topics were still to be confirmed, so check [macularsociety.org/support/winter-warmers](https://macularsociety.org/support/winter-warmers) for the latest programme.

## Dates for your diary

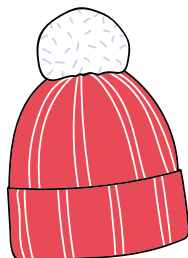
### 2021:

- 3 November
- 10 November
- 17 November
- 24 November
- 1 December
- 8 December
- 15 December
- 22 December
- **CHRISTMAS BREAK**



### 2022:

- 12 January
- 19 January
- 26 January
- 2 February
- 9 February
- 16 February
- 23 February



If you're looking for a friendly voice all year round, we can help. Among our network of more than 400 support groups, some meet virtually and others in person – find your nearest group at [macularsociety.org/groups](https://macularsociety.org/groups) or call 0300 3030 111. Or if you'd prefer regular calls with one other person, you can find out more about befriending on page 32.

Thanks to all the members who joined us for Winter Warmers calls last year, and to everyone whose support makes these calls, and all our work, possible. Without your kindness and community, we could not hope to Beat Macular Disease.



# Macular condition

## Punctate inner choroidopathy (PIC)

The PIC team from Queen Elizabeth Hospital Birmingham – **Professor Alastair Denniston**, consultant ophthalmologist **Balini Balasubramaniam**, consultant ophthalmologist **Rob Carmichael**, clinical nurse specialist and **Dr Adi Kale**, junior doctor – explain.

### What is PIC?

PIC causes idiopathic, chronic inflammation of the choriocapillaris: in other words, long-term swelling of the blood vessel layer at the back of the eye, that can't be explained by another condition. This inflammation causes a lack of blood to the retinal pigment epithelium (RPE) – the layer of cells that feeds the light-sensing photoreceptors. As the RPE starts to die off, triangular lesions like little volcanoes start to form, damaging the delicate tissues.

Around seven in ten people with PIC go on to develop choroidal neovascularization (CNV) – blood vessels which grow through these lesions, and leak and scar the retina further.

Just like other macular conditions, the sooner treatment is given, the more likely deterioration in sight can be prevented. PIC is a relatively young condition: it was described for the first time in 1984, and it's only very recently that new imaging techniques have allowed us to see the inflammation in eye tissues properly.

We know that people with PIC are likely to be short sighted, and aged between 20 and 40 when they first notice symptoms. Between seven and nine in ten people with PIC are women.

### Treatment

New blood vessels caused by CNV can be controlled with anti-VEGF

injections, as they are for wet age-related macular degeneration.

However, people with PIC have often been misdiagnosed so may have had their symptoms treated without tackling the underlying inflammation.

It can take a while, and lots of discussion between patient and

specialist, to find the right drug, or combination of drugs, to control the inflammation. These may be given as regular injections into the eye, or as a slow-release eye implant which can last for three years or more. Patients may also be offered steroid tablets, although these are less popular as they can cause various side effects if taken for a long time.

## Research

Later in 2021, our team will start a project to better understand which changes on PIC patients' eye scans are most important. We'll measure and monitor patients' lesions, and link this data with other tests, and with what patients tell us about their sight. Bringing this together could help us to start, stop, or switch treatments more effectively. It should also give patients a better understanding of how their sight is likely to change, and the warning signs they should look out for.

We'll share details on the Macular Society website once recruitment opens.

Find more about PIC at [macularsociety.org/pic](https://macularsociety.org/pic)



# Technology tips

## Cooking blind with ckbk

It might be down to habit, lack of inspiration or nervousness about trying something new, but many of us cook the same few meals every week. But if you fancy something different, a service called ckbk could help you find new recipes, and guide you through cooking them for the first time.



Ckbk is a library of 100,000 recipes, from over 500 cookbooks, with more added every month. It was created a couple of years ago, by “super-keen cook” Matthew Cockerill. “The world had become so much more digital,” he says, “so it was possible to dip into new music or movies via streaming or subscription services like Netflix or Spotify.” But the same wasn’t true for recipes, which were often only available in print, or as e-books which didn’t work with screenreaders.

When blind technologist Adrian Higginbottom pointed out how useful ckbk could be to visually impaired cooks, they worked

together to make the app more accessible to screenreaders like VoiceOver and JAWS. And it’ll soon be even more seamless – they’re currently developing an Alexa skill so it can be operated totally hands-free.

Matthew was joined by visually impaired cook Kim Jaye at an online talk for the Macular Society in June 2021, where Kim also demonstrated her delicious stuffed aubergine recipe and shared a few low-vision kitchen tips.

### How to get started

Depending on your smartphone or tablet device, search the Apple app store or Google Play store for ‘ckbk’.

The app is free to download and gives access to a limited number of recipes each month for free. Premium membership, which gives access to all 100,000 recipes, costs £4.99 a month. You can also access it through a web browser, with no need to download anything, at [app.ckbk.com](http://app.ckbk.com)

Macular Society members can try ckbk **for free** for 30 days, with no credit card required. Just go to [join.ckbk.com](http://join.ckbk.com) and use the voucher code **MACULAR30DAYS**

## Kim's tips

- Make sure the kitchen floor is clear of spills or trip hazards, and wear sturdy shoes with good grip.



- Know your oven and hob. I use tactile markings to mark different temperatures and settings – such as oven or grill.
- Make sure pan handles aren't sticking out, and don't overfill pans – use a larger one if you have to.
- The microwave can be safer than the hob or oven.
- And if you're not confident with a knife, use a food processor to chop ingredients instead.

## Other great resources

- We've collected kitchen tips and hacks from the macular community at [macularsociety.org/food](http://macularsociety.org/food)
- Find Kim Jaye's recipes, books and recommendations for adaptive kitchen equipment at [kimjaye.wixsite.com/kimjayecooks](http://kimjaye.wixsite.com/kimjayecooks)
- And you'll find Paralympic cyclist Lora Fachie's cookery blog at [blindinglygoodfood.co.uk](http://blindinglygoodfood.co.uk)



## What's your risk?



Most of us know that people whose close relatives have macular disease are more likely to develop it themselves. But do you know the other risk factors that can make macular disease more likely?

Helping people understand whether they are likely to develop macular disease, and what they can do to reduce their risk, is a big part of Beating Macular Disease. So we've produced a simple five-question risk checker. Within minutes it'll give you a personalised risk report, full of advice on looking after your eyes, the early signs of macular disease to look out for, and what to do if you're worried.

**Help us to spread the word about looking after your eyes by sharing the macular disease risk checker.**

Look out for it coming soon to [macularsociety.org/](http://macularsociety.org/)

## Website tips

Our website is one of our most powerful tools in the fight to Beat Macular Disease, whether you want to learn more about your condition, raise money, or find help.

### Quick tips for easy reading

Click the 'Accessibility Options' box in the top left corner. This will give you a series of options to help make reading easier:

- enlarging the text size
- hiding images so there are fewer distracting details
- changing text and background colour so you can find the best combination
- a 'listen' button to read the page aloud.

And if you print a page, it will automatically strip out images, blocks of colour and sidebars, so you get just the information you need, without wasting a lot of ink and paper.

Don't forget – our Connect by Tech volunteers can troubleshoot common problems with your computer, smartphone or home assistant.

Call 0300 3030 111 or email [techtalk@macularsociety.org](mailto:techtalk@macularsociety.org)

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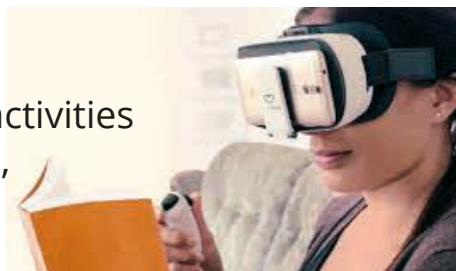
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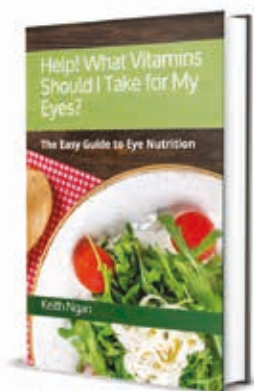


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