



Oxfordshire

Association for the Blind

Newsletter

May
2016

New Treatments

It is encouraging to hear about some of the new treatments which are being developed for certain eye conditions. In this newsletter we have an article about Retinitis Pigmentosa and we are aware of potential new surgical and medical treatments for cataracts. We sincerely hope that these and other new therapies are successful and bring benefits to many people.

We are also pleased that the Government has cancelled the planned cuts to the Personal Independence Payments (PIP) that so many disabled people rely on. We will have a short article about PIP in the next newsletter.

One of the things that I've most

enjoyed in recent months has been visiting the groups for sight impaired people around the county. I'm always struck by how much the members enjoy the meetings and we're very grateful to all the marvellous volunteers who run and support the groups. There are now three groups specifically for younger sight impaired people – ActivEyes, VIBNO and the Dreaming Spires Ten Pin Bowling Team. So, if you are interested in meeting people with similar interests, do try one of the groups. Their details are towards the end of this newsletter and I know that they will make you very welcome. I'm also pleased to let you

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Oxfordshire Association for the Blind

Registered Charity No.1140556 and Company Limited by Guarantee No. 07465300

**Bradbury Lodge, Gordon Woodward Way,
Abingdon Road, Oxford, OX1 4XL.**

Telephone 01865 725595 Fax 01865 725596

E-mail : information@oxeyes.org.uk • Web site : www.oxeyes.org.uk

Opening hours 9.00am - 4.00pm weekdays

Chair : Adrian Hill; **Vice-chair** : David Warr; **Treasurer** : George Little;

Director : Colin Cure; **Client Services Manager** : Mark Upton;

Administrator : Gail Webb; **Accounts** : Michael Ling;

Group Welfare Officer : Mary Gregory; **Information Worker** : David Thompson;

Senior Sight Advisor : Judith Wood; **Volunteer Co-ordinator** : Caroline Ludden;

Fundraiser : Rebecca Benney; **Advice Worker** : Angela Howard;

Development Worker : Ana Novakovic.

*Your Newsletter is compiled and edited by David Thompson
We are extremely grateful to Neil Stockton at Radio Cherwell
for his assistance in producing the audio edition of this Newsletter*



Director's Article

know that Angela, our Advice Worker, has had a healthy, and very smiley, baby boy. Congratulations to Angela and Paul.

I'd also like to give you advance notice that our AGM this year is on Wednesday 7th September at 2pm at the North Oxford Association in Summertown.

And finally, may I thank all those of you who joined as members recently, many of you making very generous donations too. We are delighted that so many of you have joined the Association and support the work that we are doing with sight impaired children and adults in the county and beyond.

Thank you, Colin. ■■■

Readers for Readers!

We are pleased to announce that due to the courtesy of Kidlington and Woodstock Rotary Club the libraries there now have their own CCTV Electronic Magnifiers. ■■■

Vision Strategy for Oxfordshire

We thought we would give you a little update on the national scene for developing sight loss services and then tell you a bit about what we have done locally in line with this. In 2008 the United Kingdom Vision Strategy (UKVS) was launched. The UKVS is a document that sets the direction for eye health and sight loss services nationwide. It has three main outcomes:

1) To help ensure that everyone in the UK looks after their eyes and their eyesight. Essentially this outcome is around raising awareness of eye health and promoting early detection and prevention where possible.

2) To ensure that everyone with sight loss receives timely treatment and appropriate support services. This outcome is around improving co-ordination between services and ensuring that appropriate rehabilitation is available if sight loss occurs.

3) To ensure that we develop a society in which people with sight loss can fully participate. This outcome is around improving social integration for VIPs.

As you can imagine, here in Oxfordshire, we have taken this document very seriously and we have an Oxfordshire Vision Strategy group made up of representatives from health, social care, education and the voluntary sector. The group meets quarterly and has developed a local Oxfordshire Vision Strategy modelled on the national document. After taking into account the views of VIP's (thank you to those of you that completed the questionnaire a couple of years ago) the local Oxfordshire Vision Strategy document outlines what we do well as a county and where we can direct our energy to further improve our services.

Some of the things we do well and should celebrate are the work of the Eye Clinic Liaison Officers (based at the Eye Hospital) who support VIPs at the point of diagnosis and help signpost to timely

rehabilitation. The Oxfordshire Vision Strategy group has also produced some video clips on sight loss that are being used across the county as a training resource.

If you would like more information about the work of the group or the UKVS then please ask one of the OAB team.

**Rasmeet Chadha, Optometrist
Oxford Eye Hospital. Vice
Chair Oxfordshire Vision
Strategy group. ■■■**

Saturday Opening

We have been having regular Saturday openings for the past few years and intend to continue, if required. However, we have decided to do this on an appointments only basis. So, if you would like to come and visit us, please let us know so that we can book a slot for you. Please be aware that if we do not have any appointments booked for an open day, then we may decide not to open. Our Centre will be open on Saturday 21st May from 9.30am to 12.00pm. Call us on 01865 725595 . ■■■

Land's End to John O'Groats the final stage by Colin Cure

Those of you who have been kind enough to listen when I've been talking about my cycling will know that I've been cycling around the coast of Britain, in stages, over a number of years. I started at Land's End and I've enjoyed every mile of our wonderful west coast all the way to Lochailort, to the west of Fort William. It's now time for me to complete the final 300 or so miles to John O'Groats and to do so as a sponsored ride to raise funds for our new Children, Young People and Families Service. May I thank all those kind people who have already sponsored me, and, if anyone would like to join them, I'd be most grateful. I do have a Just Giving Page. The link is:

<https://www.justgiving.com/Colin-Cure1>

If you're interested, my route will take me across briefly to Skye, back across the bridge, up past Torridon, then

Gairloch, and all the way to the north coast at Durness. I'm hoping to make a short diversion to the north west point of Cape Wrath. Then it's all the way along the north coast to the most northerly point at Dunnet Head. Yes, John O'Groats is further on and not the most northerly point. So far in Scotland I've seen lots of wildlife including eagles, dolphins and otters. I'll be there in June, so I'll have very long days. If you're kind enough to listen, when I get back, I'll be happy to tell you all about it! Thank you, Colin. ■■■

Audio Book Club

If you enjoy reading, whether audio books or print, come and join us at the next OAB audio book group. We meet on the last Wednesday of the month, to discuss the latest book and more. For more info call Mark on 01865 725595. ■■■

Decisions that changed my life

Hi, I'm Ali, originally from Aberdeen. I have been in Oxfordshire for 20 years. I am a member of ActivEyes. When I first lost my sight I was severely depressed and it took a long time to get used to it. One day I was driving my car, the next I couldn't tell the distance between me and the car in front. I turned to alcohol and food in the context of a stressful job. I have Stargardts Disease, registered blind since 2000, but retain some peripheral vision. I also have Ehlers Danlos effecting all my joints. I breathe with a machine at night and am in constant pain. I say all this to encourage anyone who thinks it's too difficult to start making small changes. I was being told I would end up in a wheelchair if I didn't change my ways.

Over the last 3 years I have lost 11 stones in weight, half my bodyweight. I was carrying around another person!! It's not been easy, but I have achieved this through diet and exercise. The weight had



Before changes

crept on over the years - too many take-aways, too much TV, working too hard to cook and doing no exercise at all. I was also on medication that caused weight gain. I was very depressed about my size and my life in general, having been forced to accept medical retirement.

I asked my Doctor to refer me to the weight loss service and joined a group that lasted for a year. The programme was



Christmas 2015

about making life changing decisions about food, exercise, alcohol and life patterns. It wasn't a diet and there was no competition or public weigh-ins. It covered the psychological aspects of eating, problem solving and nutrition. Now called More Life, you can ask your GP to refer you.

Exercise started very slowly. I would go for a dog walk twice a week for 20-30 minutes, but was too breathless to speak. I then braved the swimming

pool working up from 10 lengths, twice a week, to now doing 60.

I no longer cook, living on Wiltshire Farm Foods - mini meals (delicious, healthy without additives and colouring, instant portion control). I have fruit around all the time and reach for it first when peckish. I also don't buy-in tempting foods as I have no self-control and can still binge if the food is available.

As the weight has come off, and I get more mobile, I walk a lot more. With ActivEyes, we go cycling at Wheels for All. We have recently started VIP tennis and we have walks, pub meets and plans for so much more once the weather improves. Doing activities with friends is so much more inspiring.

I wouldn't have thought it possible, three years ago, that I now have a busy life, lots of new friends, and am enjoying my life a lot more.

My only sadness is that I didn't do it sooner

Retinitis Pigmentosa (RP)

At the time of writing this, the news has just broken of a possible breakthrough in the treatment of this previously untreatable eye condition. Research at the Oxford Eye Hospital in the John Radcliffe Hospital has had plenty of coverage in the media, so there is no need to repeat it here except to say that it could be great news for some of the 20,000 people in the UK who have retinitis pigmentosa. To support this there was a report in The Times on 28th January headed 'Genetic Engineers are close to cure for inherited blindness', and it specifically mentions RP.

With RP the retina deteriorates from the outside towards the centre, causing loss of peripheral vision, resulting first in tunnel or pinprick vision and then eventually blindness. It attacks people of all ages from the very young to the much older and the lady who has just been treated at the JR was first diagnosed when she was only five years old. Although the rate of decline differs the

end result is always the same. There are about 200 sufferers in Oxfordshire and the Oxfordshire Local Group is part of the nationwide network of groups coming under the umbrella of the national body called RP Fighting Blindness which this year celebrates its fortieth anniversary. Our local group has twenty-four members of whom fifteen have RP. Its function is to provide advice, organise social activities and to raise funds for research. We raise funds by various means: store collections, the monthly token schemes offered in several stores, and sponsored events, particularly walks. Every penny we raise goes to the RP Fighting Blindness Medical Research Fund, which makes grants approved by its own Medical Advisory Board. On the social side we have an annual lunch in January (recently we had a splendid meal at a restaurant in Abingdon), a summer barbecue, visits to the theatre for audio-described

performances and meetings with speakers on RP and a wide range of other topics of general interest.

To find out more about RP and the charity have a look at its website at: www.rpfightingblindness.org.uk and if you would like to learn more about the Oxfordshire Group, do please contact our committee members. They are:

Steph Etherton.

Tel. 01865 876416. E-mail: steph@metherton.freeseerve.co.uk

Peter Jackson.

Tel. 01865 873246. E-mail: peterjackson25@hotmail.com

Sue Sambrook.

Tel. 01235 521010. E-mail: smsambrook@icloud.com

Savita and Tara Shah.

Tel. 01235 529136. E-mail: tpshah51@onetel.com

Chris Turner.

Tel. 01235 511044. E-mail: optimistic@phonecoop.coop

**Peter Jackson, Group
Chairman ■■■**

VIBNO

VIBNO is a group for the 18 – 50 age group in Oxfordshire to meet socially and have fun.

We meet once a month on the second Wednesday of the month. Our meetings include having a drink and a chat at a pub, dining, playing skittles and Aunt Sally and visiting places of interest.

So if you are a VIP aged between 18 and 50 and want to socialise and have fun with people alike come and join us. Partners, friends and family are welcome to all events.

Since the start of the year we have enjoyed a drink and a catch up at the Black Horse Pub in Kidlington, had a very interesting touch tour of Sulgrave Manor and enjoyed the buffet at Oxy Oriental.

For more information and details of our programme please contact Nicola Pamphilon 01869 331778 or e-mail : flashnp@aol.com



Charles Bonnet Syndrome

“I do wish these people would get off my sofa” writes Judith Potts. With these words my independent elderly Mother, Esme, broke her year-long silence about her ‘visions’. “They go, if I tap them on their shoulders”, she continued, while I tried to reassure her there was no one there – all the time conscious of the word ‘dementia’ hanging in the air.

With a startling piece of luck, that very day, I read a short paragraph in one of the newspapers about something called Charles Bonnet Syndrome (CBS). It could have been written by my mother. Her eyesight had been deteriorating for some time, since glaucoma had been missed by her optometrist – but she still managed the Telegraph crossword every day.

OAB Comment : Many visually impaired people have similar stories of visual hallucinations and how it has affected them. It's caused when

vision has been lost, so the brain makes up for lost signals by creating its own. Often people see images of the past, and it often happens when the person is resting. This may not always be the case though. It can be extremely distressing for a lot of people - like Judith Potts says, she thought her mother had dementia. If you experience these images, it is important for you to know that you are not alone.

Although we can't put all the information here, we are happy to advise you on CBS and/or supply you with large print information, so please call us on 01865 725595 for more information, we will be happy to help.

Judith runs Esme's Umbrella, a campaign to create awareness of Charles Bonnet Syndrome.

Telephone :
0345 051 3925.

Website :
www.charlesbonnetsyndrome.uk



Fundraising Update

We are indebted to our many friends who help to fund the services we provide – your support is crucial to our work and we are grateful for all amounts received. There are many ways in which you, or someone you know, could help us with fundraising. An update on some of these is given in the articles below.

Annual Raffle

The annual OAB Raffle draw will take place this October and in the next (August) edition of the newsletter we will be including two books of 10 raffle tickets for each reader to purchase themselves or sell to family and friends. If you would like us to send you more than two books of tickets, please call or email us and let us know how many you would like. Alternatively, if you would prefer that we do not send you any raffle tickets, please let us know. Thank you. ■■■

Keep on recycling

We still have a recycling box here at OAB and we can accept the following items: unwanted or broken jewellery (in all materials), unwanted currency (from any country and of any age), gadgets (such as mobile phones, tablets, video cameras, sat navs and iPods of any age) and stamps (including albums). Smaller, lighter items such as unwanted or broken jewellery or old banknotes can also be sent directly to the recycling company via Freepost. We can provide you with special envelopes in order to be able to do this. If the items are heavier or more bulky, we may be able to collect them from you. Please give us a call to arrange this. OAB receives income from all items that are re-cycled. ■■■

Oxford Events

Following the success of last year, we are again seeking to enter a team in this year's Bike Oxford sponsored cycle ride on 11th September. Starting and finishing in Oxford, riders can select one of three circular routes of a different distance and challenge taking in some of Oxfordshire's finest scenery whilst raising funds for OAB. For those who prefer running, the Oxford Half Marathon takes place on 9th October. It is still possible to sign up to run for OAB via the Oxford Half Marathon website at <http://oxfordhalf.co.uk/>

We will provide all those taking part with fundraising support and an OAB running vest. ■■■

Organise your own event

From coffee mornings to sponsored silences, there are many ways to organise an event in support of OAB. Why not get other family members and friends involved? We can provide you with fundraising support and offer ways to help

you with your event. Please contact us if you would like help with an event or to discuss your ideas. ■■■

Oxford Rotary Fun Run

We would like to say a huge 'thank you' to everyone who took part in the Oxford Rotary Club Fun Run on Saturday 7th May. We had a fantastic team representing OAB, including many visually impaired children and their family members. A full report and photo will appear in the next edition of our newsletter. ■■■

Legacies

Leaving a donation to OAB in their Will is something that several of our supporters have done in previous years. If OAB has touched your life and you would like to leave a lasting legacy to an important local organisation, then please consider us. For more information, or to speak in confidence about leaving a legacy to OAB, please call 01865 725595 and ask to speak to Colin Cure. Thank you. ■■■

Sulgrave Manor Touch Tour

In March, 13 of us from VIBNO met at Sulgrave Manor Near Banbury for our very own specially designed touch tour of the manor.

The tour came about when I previously visited the Manor and asked if they did any touch tours for visually impaired people, to which I was told “ We don’t have one at the moment, but we could design one for you”.

The tour started with an introduction to the Manor’s history and how it is linked with George Washington.

Whilst in the house, we learned how they drank their tea, not from a cup, but slurped from a dish!

We then spent time in the kitchen feeling heavy cookware and smelling a variety of herbs, which they used to cook with. Upstairs, we visited bedrooms where we got to feel some of the clothes they wore and then finally to the dining room where we felt the food laid out for the family.

It was really interesting to learn lots about the history of

Sulgrave Manor and having the opportunity to touch a wide variety of objects during the tour. We finished off the afternoon with a delicious cream tea.

We would like to thank the staff of Sulgrave Manor for all the work they put into designing and delivering the touch tour.

Nicola Pamphilon ■■■

Museum Touch Tours in Oxford

Oxford University museums are offering hour long, themed, touch tours for visually impaired people starting at 11.00am on the following dates:-

Thursday 26th May Objects on the Haida people, Pitt Rivers Museum.

Thursday 30th June Objects of navigation and exploration, Museum of the history of Science.

Thursday 28th July Insects, Museum of Natural History.

Thursday 25th August Masks, Pitt Rivers Museum.

Thursday 29th September Objects of Science, Museum of the history of Science.

To book a place please contact Susan Griffiths on 01865 282456.



He looks after the trees!

We are grateful to South Oxfordshire District Council for this edited article from their Outlook magazine ■■■

A day in the life of a Tree Officer.

We have around 10,000 trees on district council land in South Oxfordshire, and our tree officer, Robert, looks after them all. Robert told us about a typical day in – and mostly out of – the office. “My role is to make sure that the council’s trees are maintained and safe. We don’t want branches falling and damaging people’s property. I check all our trees on

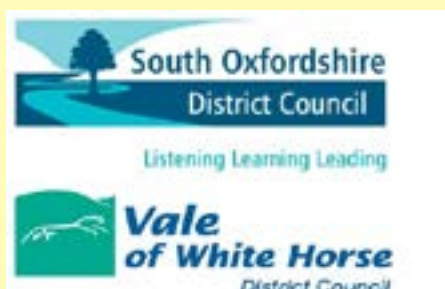
a one to five year basis, depending on their age, location and condition. When I’m inspecting a tree, first of all I will map its location and species on our system – or if it’s recorded on the system already, I’ll check if its details need updating. This involves taking measurements of height, girth and crown spread. I also check to see if the tree is healthy – looking for signs of disease or damage. If necessary, I’ll record any treatment work that needs doing, or plan to plant replacement trees – I’m really happy that I’m able to look after the district’s trees. I enjoy spending time outdoors and it helps that I’m a really big fan of trees.” ■■■

The work of the Oxfordshire Association for the Blind is assisted by funds from



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www.oxford.gov.uk



Clubs and groups for VIPs in Oxfordshire

Abingdon Macular Group

Eleanor Dangerfield
01235 531857

ActivEyes

Guy Lawfull 01865 725595

Banbury Macular Group

John Critchlow 01608 685293

Banbury Society for the Visually Impaired

Enid Smith 01295 269568

Carterton Visual Impairment Group

Rosemary Pearse 01993 841383

Chipping Norton Friends of the Blind

Mary Gregory 01608 810899

Didcot/Wallingford

Pam Organ 01235 813391

Goring Macular Group

OAB 01865 725595

Henley VIP Group

Mike Pooley 01491 628284

Look Oxfordshire Support for families of VI children

Julie Hinton 01189 722322

Kidlington Macular Group

Tom Wright 01865 376482
Marita Ferrett 01865 373104

Oxford Macular Group

Daphne Dorman 01993 811084

Oxfordshire Retinitis Pigmentosa Group

Peter Jackson 01865 873246

“OXVIC”

Oxford Visually Impaired Club OAB

01865 725595

“Oxpots” Pottery Class

Angie 01865 373251

Thame and District Society for the Visually Handicapped

Jean Mander 01844 212983

“VIBNO”

Visually Impaired But Not Old!

Nicola & Kevin
Pamphilon 01869 331778

“VIVA”, North Oxford

Liaison Officer
Ron Sears 01865 553063

Wantage Blind Social Club

Mary Greenfield 01235 764646
Secretary

Hazel Aldred 01235 765849

Dreaming Spires Ten Pin Bowling Club

Kevin Pamphilon 01869 331778

Witney Macular Group

Sarah Salcombe 01993 771828

Oxfordshire Social and Community Services Sensory Impairment Team

A countywide team of specially trained staff supporting people of all ages affected by sensory impairment

Manager John Fearn-Webster

Visual Impairment Team

Beverley Downs

Kate Laybourne

Meg Jones

Serena Glister

Jessica Brown

Senior :

Elizabeth Agar

Telephone 01865 894935

visual.impairment@oxfordshire.gov.uk

Hearing Impairment Team

Zelda Yarker, Catherine Thurbin,

Ben Smith

Rebecca Nolan,

Mark Cove

Senior : Neelam Ahmed

Telephone 01865 894925

SMS - 07713329501

Sensory Impairment Team

Abbey House

2nd Floor

Abbey Close

Abingdon

OX14 3JD

Out of hours social services, emergency freephone 0800 833408



Carers Oxfordshire

A service for all carers



To make it easier for Carers to access support

To listen to Carers' needs

To give information, advice and support to Carers

Please telephone 0845 0507666
Or email carersoxfordshire@oxfordshire.gov.uk
Or go to www.carersoxfordshire.org.uk

