

## **BucksVision Winter 2018 Newsletter**

We do hope that you look forward to receiving our newsletter and find the articles interesting. If you have any suggestions for improvements, please do let us know.

## Contents [Elfvis]

Welcome – Steve Naylor, Chief Executive.....	2
ECLO update.....	3
Woburn Safari Park Trip.....	4
“Aren’t We Worthy?” .....	5
BucksVision Volunteer Survey .....	7
We need your views! .....	8
Pizza Express Marlow .....	9
RNIB Network SE Needs you!.....	10
Charles Bonnet Syndrome .....	11
E-Libraries and Reminiscing .....	13
Low Vision Clinic .....	14
Equipment Demonstrations .....	15
Community Sensory Garden, Bletchley .....	16
A Walk in the Park.....	17
Let’s Get Social! .....	18
Adverts.....	18
Useful Contacts .....	19

## **Welcome – Steve Naylor, Chief Executive**

Another year has almost passed, and I already find myself looking ahead to next year. How will the world change around us? How do we ensure that we help local blind and partially sighted people in the best way possible? How will technology and social media impact our work?

Whilst I confess to not knowing the answers to these questions, I do know that it is crucial to involve everyone in our work, particularly the people that we are here to support and our volunteers who generously give their time to help others.

One of the first steps in doing this is to seek people's views, and many of you will know that we recently carried out a comprehensive Volunteers' Survey. This was an important first step in improving the ways that we support our volunteers and the feedback that we received was very useful (see page 7). Equally important is that we seek the views of the blind and partially sighted people whom we are here to support. We will be seeking the views of our members in the months ahead, with a view to evaluating our current services as well as considering new ones for the future.

However, before I go wishing the year away, let me offer gratitude for all of your support throughout *this* year. Thank you so much.

I hope that you enjoy reading our Newsletter and wish you and your loved ones a wonderful Christmas and a healthy and prosperous New Year.

## **ECLO update**

Across the UK, Eye Clinic Liaison Officers (ECLOs) provide early intervention support, enabling patients and their families to understand their sight loss diagnosis, receive quality information and support, and connect with vital services.

Last year BucksVision was successful in placing an ECLO at Stoke Mandeville Hospital and as you may remember in our Autumn newsletter last year we introduced you to Ellie Richmond, who had been recruited as our ECLO. Sadly, in November Ellie resigned to begin a new adventure in Somerset.

We are therefore in the process of recruiting a new ECLO and we hope to be able to introduce them to you in the Spring Newsletter.

### **Overview of the past year**

As the ECLO position was new to the Hospital it took time for it to be embedded into the Eye Clinic.

However, over the last six months the number of patients Ellie helped rose significantly, with 50-60 patients being helped each month (face to face, email or telephone support).

Ellie was able to help and provide vital information on a wide range of queries, from blue badge applications, to low vision clinics and sensory service support.

If you still have questions or need further support, please give us a call and we will assist you.

**Tel: 01296 487 556**

**Email: [reception@bucksvision.co.uk](mailto:reception@bucksvision.co.uk)**

# **Woburn Safari Park Trip**

On Monday 17 September a group of twenty six of us boarded a coach to visit Woburn Safari Park.

Our day started with a drive around the road safari. We had booked a guide for this part of the trip so he could provide information about the animals and help describe where they were for anyone with some sight.

After the road safari we were dropped off at the main park where we enjoyed some lunch before we moved on to the afternoon section of our trip.

The first hour was a chance to get up close to some of the Woburn residents. These included a tortoise who was blind in one eye and a partially sighted owl!

Everyone got a chance to meet and touch these animals as well as find out more about them from the keepers.

Our next stop was the lorikeet room where anyone who wished to was given a pot of nectar to feed the lorikeets- this was great fun as the birds landed on the members to be fed.

The final part of the day involved a foot safari when we were once again joined by two guides who took us around some of the main enclosures of the park including the penguins and lemurs.

After all of this everyone happily boarded the bus back to central Milton Keynes.

A big thank you to Woburn Safari Park for helping organise the trip. We had a fantastic time!

## **“Aren’t We Worthy?”**

Back in our Summer Newsletter we mentioned that one of our volunteers, Philippa Atkinson, based in the Buckingham area, had been chosen as one of the women featured in the “Aren’t We Worthy?” exhibition at Stowe (NT) which ran from 10 September to 9 November.

Philippa was invited to attend the official opening ceremony on Wednesday 19 September. And our Walking group visited the exhibition on 15 September, followed by staff members on 5 November.

We were very proud to see Philippa amongst the other women chosen.

The exhibition consisted of sixteen Perspex boxes each containing art work that related to the person it was celebrating. The exhibition mirrored the existing Temple of Worthies which contains sixteen busts, fifteen men and one woman. Prompted by a comment from a visitor asking, “Aren’t women worthy?” the exhibition sought to reverse this by creating a temporary temple consisting of fifteen women and one man.

Local community groups were invited to nominate five of the women for the exhibition, and we were delighted to nominate Philippa as she has been pivotal in supporting our services in the Buckingham area.

Other organisations involved included Eve which runs a Family Refuge in Northampton; Mia’s Wood, a children’s environmental charity; MK Snap which supports individuals with learning disabilities; and MK Young Embroiderers. Two more of the women were chosen by local schools.

The final nine women were chosen from a shortlist of public/famous women by Stowe Visitors and included Queen Victoria, Queen Elizabeth II, JK Rowling, Edith Cavell and Beatrix Potter. Finally, the only man in exhibition, chosen by Stowe, was Sir David Attenborough.

The artwork for Philippa's display was designed and created by the COBB craft group which meets at Stowe and has a long history with the venue. Philippa's image was used to show the different ways sight loss can affect people's vision. The base of the display consisted of printed words and quotes, used by the group to describe their sight loss and the impact it had on them. These words included "The walls close in", "Life through a net curtain" and "Determination".

We feel honoured to have been part of this exhibition, and would like to thank Philippa, COBB members and volunteers, and Stowe staff and volunteers for all their hard work.

# BucksVision Volunteer Survey

During the summer, we conducted an anonymous Volunteer Survey, with the aim of providing us with a picture of what we are doing right and where we can improve our volunteer support.

124 Volunteers responded (over 50% of volunteers surveyed), with an even split of gender, and it was clear from the responses that people had been given the opportunity to express their views freely.

We were pleased that 90% of volunteers who responded were likely or very likely to recommend BucksVision to a friend or colleague, with 91% of volunteers rating their voluntary experience as good or excellent.

*“I think BucksVision do very well supporting their volunteers. In the past I have volunteered for a very large organisation and had no acknowledgement for my efforts and finally left partly because I felt unappreciated.”*

These are hopefully reassuring results and demonstrate that we are an organisation people want to volunteer for.

The survey has also helped to set clear objectives for improvement and change. For example, we need to give volunteers a chance to openly engage with us on subjects such as fundraising, volunteering and governance; to explore other ways of delivering training; and to better utilise the skills of our volunteers.

*“I think you are going in the right direction and good to see the improvements /progress that have been made in the 6 years I have been volunteering for you.”*

We would like to thank everyone who took part in the survey. We value your feedback and we hope that over the coming



months you will continue to see positive changes which show that we have listened to you.

## **We need your views!**

Following our Volunteers' Survey, we are planning to survey our Members to find out what we are doing well, what we need to improve and whether there are any other services that we might develop.

Without our members and volunteers, we would cease to exist so we are extremely keen to hear what you think about us and what you think we should be doing, so we can ensure our services continue to be relevant within our changing society.

We will be seeking your feedback on our existing services and how useful they are; other support that is available and will ask for your suggestions for other services that we could be delivering.

The survey can be completed by phone, by post or online (via the website Survey Monkey).

We will be distributing the survey in the New Year to a random selection of our membership, but if you would like to take part please contact Alison Deuchars to register your interest.

**Tel: 01296 487 556**

Email: [adeuchars@bucksvision.co.uk](mailto:adeuchars@bucksvision.co.uk)

## **Pizza Express Marlow**

We have held several pizza making events across Bucks, which have been good fun and very popular.

Nonetheless, our recent visit to Pizza Express Marlow, on Tuesday 20 November has been the best so far.

Our hosts, Valentina and Laert were exceptionally attentive to all our needs, from remembering everybody's name to encouraging everyone to toss their pizza dough as high as they could.

They even held a competition for "Best Pizza" which was won by Wycombe Division's Mary and Barbara who both received a complementary drink.

There was lots of laughter, and very full stomachs, and everyone left with a smile.

We would like to say a very big "Thank You" to all the staff at Pizza Express Marlow for a wonderfully messy afternoon.

# **RNIB Network SE Needs you!**

RNIB are looking for people who want to help shape their work in the South East of the country by joining their 'Network Committee' and getting their voice heard.

## **What will you be doing?**

Working with committee members and staff to help lead and steer RNIB's work in the community, bringing positive change for anyone affected by sight loss.

## **What skills do you need?**

None! They welcome people who want to contribute their own experiences and knowledge of the issues faced by people with sight loss and who are committed to representing the best interests of people with sight loss across the South East. They want to hear from people who feel positive about RNIB's future work to support people living with sight loss.

## **How much time would I need to give?**

The Committee meetings are once every three months for 4 hours maximum. There will also be opportunities to get involved in volunteering and specific projects relating to the work of the committee. Meetings may be face-to-face, telephone or Skype.

## **How do I apply?**

Please email Community Facilitator **Brian Anderson**, [ConnectSE@rnib.org.uk](mailto:ConnectSE@rnib.org.uk). Put Network Committee in the subject area, telling them why you want to be part of the committee and what relevant experience, knowledge and skills you feel you can contribute.

The closing date for applications is 31 December. Shortlisting and an informal interview will form part of the appointment process.

**Thank you and we look forward to hearing from you!**

# Charles Bonnet Syndrome

Have you ever experienced vivid, silent visual hallucinations?

If you have then you could be experiencing Charles Bonnet Syndrome (CBS).

CBS occurs when people with sight loss experience silent, visual hallucinations. They can range from seeing dots and shapes to seeing insects, people and large objects. The hallucinations can be terrifying especially if you see people in your house or if a wall suddenly appears in front of you as you are walking along.

CBS, without other signs of mental health problems, is not a sign of mental illness but can be compared to Phantom Limb Syndrome. This is experienced by people who have lost a limb but still feel its presence or it tingling; in CBS the brain is filling in the gaps left by the loss of vision by creating its own images.

Sufferers of CBS often fear telling anyone they are experiencing hallucinations as they fear being diagnosed with a mental health condition or being tested for Dementia so can often feel isolated and alone. CBS can also cause anxiety, stress and exhaustion as people become unsure of what is real or not.

As a result of this, Judith Potts, whose mother had CBS, set up Esme's Umbrella to raise awareness of the condition and we are delighted to support her quest, which also involves developing research into the condition. And in line with this, a staff member attended the first CBS Conference in London on Friday 16 November to find out more about her progress.

## Conference 16 November 2018

Research by Esme's Umbrella finds that only 17.2% of people are asked by their Ophthalmologist if they experience hallucinations, even though Ophthalmologists are taught

about CBS. Esme's Umbrella hopes to improve this statistic through raising awareness and education.

There is currently a two-year research study taking place in Newcastle. Participants who regularly experience CBS are being invited to take part. Brain scans of people with CBS show what brain activity occurs when the hallucinations happen.

It has been found that CBS tends to be at its worst when people have a sudden deterioration in their vision, or if they are stressed. It can go on for years and as yet, there is no cure.

### **Helpful tips**

If you have CBS, here are some helpful tips for coping with the condition:

- Get plenty of sleep
- Change your focus e.g. play music or move to a different room
- Get some fresh air
- Swat the hallucinations away or try and touch them
- Change the lighting e.g. turn on lights if it is dark and vice versa.

### **What help/support is available?**

If you think you may be experiencing CBS you can contact the RNIB Eye Health Team, who are working in conjunction with Esme's Umbrella.

**RNIB Eye Health Team** 020 7391 3299

Alternatively, if you experience CBS and would like to speak to others with the same condition you can call the RP Fighting Blindness helpline.

RP Fighting Blindness  
0845 123 2345

## E-Libraries and Reminiscing

Did you know that you can download eBooks and eAudiobooks from your local library?

Buckinghamshire Libraries use a system called *Borrow Box* which can be accessed via the Library Service's website or by downloading the BorrowBox App.

For Milton Keynes (MK) residents, MK library uses a different system called *RBDigital*. Again, it can be accessed through the MK Library website or by downloading the App.

Milton Keynes library also offers a service called *PressReader* which provides access to complete digital newspapers and publications from all over the world (including translations).

All you need to access these services is to have a valid library card.

### Reminiscing

Buckinghamshire Libraries Reminiscence Collection includes items designed to stimulate the mind and the memory. Items can be borrowed free of charge and are available to anyone with a library card. The collection is in Aylesbury but can be sent to any library in the Buckinghamshire County Council area.

There are 277 items in the collection, but BucksVision has put together a list of the most tactile and sensory ones (a copy can be requested from us).

Examples of some of the items include:

- Suitcase of history – WWII
- Traditional toy box
- Scentscape: At Home
- Getting ready to dance (box)

**To book and borrow the items please call 01296 382 415 or speak to local library staff.** Please note reminiscence items cannot be booked online.

## **Low Vision Clinic**

**If you use magnifiers to read, do you know that you can get help with magnification through the NHS? This service is called the Low Vision Clinic and can be accessed via a referral from your GP.**

At the clinic an Optometrist will test your sight and determine what strength magnification you need to comfortably read as well as showing you how to use a magnifier.

This is essential as it is very important you use the correct magnification – too strong or too weak magnifiers will make it harder for you to read comfortably.

At the end of the clinic you will generally be provided with a handheld illuminated magnifier on loan free of charge.

If you have already been seen at the clinic or do not wish to access it, then BucksVision is able to provide magnification support, by giving you an idea of what strength is best for you and advising on the different types of magnifiers available. See page 15 for more information.

Please note, we do always advise people to request an appointment with the Low Vision Clinic in the first instance.

## Equipment Demonstrations

Back in May we celebrated the 30<sup>th</sup> Birthday of our Office and Resource Centre in Aylesbury by opening our newly refurbished Resource Room.

Since then, we have worked on improving the range of equipment we can demonstrate to people and we now have an even wider range of magnifiers, both hand held and electronic for you to try out, as well as our many daily living aids.

If you are interested in a particular item, please don't hesitate to contact us as we may already have it in stock or may be able to show you similar products. Sometimes we can even order it in for you to try out, so don't be afraid to ask.

If you would like visit the centre please remember to make an appointment. You can make an appointment anytime between **10am and 3pm Monday to Friday**. Appointments generally last one to two hours depending on how much you wish to look at.

If you would like to visit but cannot get to Aylesbury, please let us know as we may be able to arrange volunteer transport for you.

To book an appointment, call **01296 487 556**.

And don't forget, if you live in Milton Keynes we also have a volunteer run resource centre based at Age UK's Peartree Centre in Chadds Lane which is open Tuesday afternoon (1pm-4pm) and Wednesday morning (10am-1pm).

**Tel: 01908 395 498**

Outside of opening times you will be diverted to Aylesbury office.



# **Community Sensory Garden, Bletchley**

In 1965 the Bletchley/ Buckingham branch of *Toc H* conceived the idea of creating a scented garden for the blind.

The garden was once part of the rectory garden adjacent to St Mary's Church and was formally opened by the Lord Lieutenant of Buckinghamshire (Brigadier Sir Henry Floyd, CB CBE) and President of Bucks Association for the Blind, in 1967.

Through time the garden has both been looked after and neglected, but when local resident volunteers took on the challenge it was badly overgrown.

During 2016 the site was cleared and through generous donations and volunteer assistance from local businesses and BucksVision the Garden was transformed.

It was re-named as the Community Sensory Garden and was entered into the RHS Thames and Chilterns 2018 Britain in Bloom competition.

It was placed in a group of 22 entrants entitled 'It's Your Neighbourhood' and the judges awarded the Garden the level 'Advancing' (equal to Bronze).

Plans for the Garden's future development are already in place.

## **A Walk in the Park**

BucksVision's Aylesbury Walking Group certainly made the most of the outdoors during our lovely summer weather. In June we walked down part of the Phoenix Trail between Thame and Princes Risborough, while a very hot July took us to the shade of Wendover Woods. August saw us tackle a much more challenging ramble through Tring Park.

While in September we went to Stowe, where we were able to explore monuments such as the Pebble Alcove and the Temple of Worthies and visit the exhibition entitled "Aren't We Worthy?" which featured our North West Vice Chair, Philippa Atkinson (see page 7 & 8).

We were all quite tired by October, so we had a relaxing stroll around Coombs Woods, Padbury. For our final walk of the year we explored Whiteleaf and Brush Hill and enjoyed some well-deserved refreshments in the George and Dragon afterwards.

Our walks take place on the last Saturday of the month starting at 1pm. Everyone on the walking group mailing list receives an invitation detailing the venue, length and terrain of the walk and can then book a place if they wish to attend.

Guides and transport can be provided to members, but companions are also welcome to come along. So, if you would like to join our mailing list, please phone the office on 01296 487 556 and speak to Lisa Redford.

### **2019 Dates (locations TBC)**

26 January

23 February

30 March

27 April

25 May

29 June

Walking Groups are also available in Milton Keynes.

## **Let's Get Social!**

You may have heard the term Social Media used frequently in the news but do you know what it means?

Social Media refers to websites and applications that enable users to create and share content (photos or comments) or to participate in social networking. There are many platforms but the most well-known are Instagram, Twitter and Facebook.

And if you use social media, why not follow us, as during December... **Elfvis is in the room.**

We will be running a series across our social media channels (Facebook, Twitter and Instagram) on "What is Elfvis up to now?" Elfvis is a friendly Elf who will be spending December with the BucksVision team.

We have hidden his name, Elfvis, somewhere in the newsletter – if you find it let us know and you will be entered into a draw to win several small prizes. This competition ends on 21 December 2018.

### **Interesting groups/people to connect with**

**Blind New World** – Facebook, Twitter and Instagram

**Lucy Edwards** – You Tube

**Bold Blind Beauty** – Instagram

### **Adverts**

#### **Calendars and Diaries**

2019 is nearly here so don't forget to order your large print calendars and diaries!

A6 Pocket Diary - £5.75

A3 Calendar - £6.25

### **Second Hand Equipment**

#### **Reinecker Mezzo CCTV Magnifier**

Approximately five years old. £400 but will accept reasonable offer. Would need to collect from Wycombe area.

## **Useful Contacts**

### **Bucks Integrated Sensory Service – 01296 479970**

(For support dealing with sight loss at home in Buckinghamshire)

### **Sensory Advice Resource Centre – 01908 401135**

(For support dealing with sight loss at home in Milton Keynes)

### **RNIB – 0303 123 9999**

Advice and support with all aspects of sight loss.

### **Macular Society – 0300 3030 111 (Helpline)**

Information and support for people with macular conditions

### **Age UK Bucks – 01296 431911**

Support for older people living in Buckinghamshire to help them achieve and maintain independence and wellbeing.

### **Age UK Milton Keynes – 01908 550700**

Support for older people living in Milton Keynes to help them achieve and maintain independence and wellbeing.

### **MK Reader Service – 01908 231123**

Support with reading and shopping in Milton Keynes.

### **British Wireless for the Blind – 01622 754757**

Radio sets on free loan for people who meet the criteria.

### **Esme's Umbrella – 020 7391 3299**

Support for people experiencing Charles Bonnet Syndrome via RNIB Eye Health Team.

### **BucksVision – 01296 487 556**

143 Meadowcroft, Aylesbury HP19 9HH

[www.bucksvision.co.uk](http://www.bucksvision.co.uk)