

# WCB Roundup

Spring 2010.

## Tourism & Holidays



### Also in this issue:

UK Vision  
Strategy Update

Focus on  
Nystagmus  
Network

Local News



Photographs by Sandy Davies

A newsletter for Local VI Groups in Wales

# One Agency Wales?

In the summer of 2009, Leslie-Ann Alexander, the RNIB's Chief Executive, wrote "If I had my way, we would have one national sight-loss charity that was responsible for campaigning, infrastructure, strategic marketing and quality initiatives, and a whole carpet of local sight-loss charities delivering services within a framework." The article, published in the Third Sector Magazine, went on to publish her view that that the visual impairment sector would be best served by a having a single agency essentially running the whole visual impairment charitable sector, presumably that agency being the RNIB itself.

One model that the RNIB have increasingly used is that of collaboration or merger. In England, Action for the Blind are now part of the RNIB, as are several other agencies. In Wales, RNIB Cymru have taken over Cardiff Institute for the Blind, and entered into partnerships with other smaller societies. In March this year, the RNIB invited larger charitable agencies within the VI sector to consider joining the RNIB Group.

WCB is looking to ask the VI sector in Wales what they think of the idea of one agency coordinating all charitable sector organisation in Wales?

There's a lot to discuss around the issue. Would Wales best be served by being coordinated by a single UK-wide organisation?

As WCB engages with partners from across the sight loss sector, there's a lot of discussion around the issue. Some see a single agency Wales as an opportunity to streamline efficiency and develop a more corporate response to the growing challenge of providing support in a time of economic darkness. It's an argument that may have validity. A well coordinated Welsh wide service run by a single agency should be streamlined and effective. And isn't that what we are here to do? To offer the very best service to people with a visual impairment? There are others in the sector that see the creation of a single agency Wales as a risk. Any single-agency model by its very nature decreases choice and diversity. Some unfavourable critics perceive

the RNIB as an agency concerned more with money and power than service delivery, whilst others see a one-agency Wales as putting all the eggs into one basket. Does Wales really benefit from strategy and direction that is ultimately led from England?

One thing that Wales must do is openly debate the merits of a one-agency Wales. Local societies in Wales need to have a clear idea of what future they want to see, and the conviction to deliver against that.

## The UK Vision Strategy.

The UK Vision Strategy is a VISION 2020 UK initiative to develop a unified plan for action on all issues relating to vision across the four countries of the UK. It was launched in April 2008 in response to the World Health Assembly VISION2020 resolution to reduce avoidable blindness by the year 2020 and improve support and services for blind and partially sighted people.

The Wales Vision Strategy Implementation Plan 2010 to 2013 sets out the Welsh commitment to deliver against the three priorities within the UK Vision Strategy.

The Wales plan has been produced by the Wales Advisory Group which includes representation drawn from many professional groups involved in delivery services for people with sight loss and those involved in prevention of sight loss.

The Vision Strategy presents an opportunity for Wales to build on progress that has already been achieved in Wales. The objectives cannot be addressed by one sector or one organisation. A co-ordinated approach is needed to maximise the effectiveness of scarce resources and deliver sustainable change at a strategic and operational level.

The challenge cannot be understated as the number of people with sight loss is projected to increase significantly by 2020. The

prevalence of sight loss in Wales is 9 percent above that of England. Eighteen of the twenty two local authorities in Wales have a higher prevalence than England due to a much greater proportion of people aged over 65 years.

This Implementation Plan has three key outcomes which mirror those of the UK Vision Strategy:-

(1) Improving the eye health of the people of Wales

(2) Eliminating avoidable sight loss and delivering excellent support to people with sight loss.

(3) Inclusion, participation and independence for people with sight loss.

All four governments of the UK have given the UK Vision Strategy their support and have country plans and steering groups in place.

The Wales Vision Strategy Advisory Group includes representation from professionals across the sectors, including neurologists/ neuroscience researchers, orthoptists, optometrists, ophthalmologists, Royal College of Nursing, Wales Council for the Blind RNID, RNIB Cymru, NALSVI, The Guide Dogs for the Blind (Guide Dogs), social services and the Welsh Assembly Government.

A copy of the Wales Strategy can be found at our website, [www.wcbccd.org.uk](http://www.wcbccd.org.uk) after its launch in spring 2010.

## What do you think?

As the second issue of Round-Up comes out, we at WCB still want to make sure that we're producing the right information for you. Last issue we asked what you'd like to see in forthcoming issues, and would like to thank those of you who responded.

All of the five societies who responded were particularly concerned

about issues affecting older people, with two also interested in visually impaired children and young people. Three societies wanted information concerning leisure and social activities, with none of the respondents expressing an interest in employment issues. Regarding specific topics of interest, the main demand was for news items from other VI societies in Wales, and the opportunity to discuss issue and share ideas via a letters page. Several of the respondents were also in favour of a regular column giving information and contact points for a different, relevant topics in each issue – as you will see, we are covering holidays in this issue. There was less interest in news of funding opportunities, technology tips or provision of fact sheets printed from the internet.

In response to the questionnaire, one society mentioned the difficulty of finding officers, and keeping the organisation going when most members are elderly and in poor health. It would be interesting to hear whether any other groups have the same problem, and if so, whether they have any solutions to offer.

However, many societies have not yet responded, and we really want to hear about what your needs are. Would you prefer to hear about what is happening nationally, or would you prefer to see more regional pieces to do with the area you operate in? Do you prefer to hear international and UK wide initiatives, or purely Welsh items? We really need to hear your views to make this publication valuable to everyone in the visual impairment sector.

## **The State of the Third Sector in Wales.**

In order to deliver against our role of umbrella agency WCB will in the next few weeks be developing a programme of research that will map service provision by the third sector in Wales. The programme will be rolled out over several months and will include a thorough and comprehensive review of the national agencies, local societies, organisations, and clubs throughout Wales concluding with the publi-

cation of a report of the findings.

Previously undertaken by WCB on several occasions, this exercise has proved to be a useful tool in providing a map of service provision; however, following much development and expansion of the third sector an 'up to date' record is now needed that will provide a complete and accurate overview of the third sector working in Wales and a comprehensive and detailed record of their service delivery throughout Wales.

An accurate and complete picture of service provision by the third sector throughout Wales is necessary to enable WCB to demonstrate the scope and importance of the third sector and highlight the need for additional services and therefore a good response to the programme will be essential.

WCB would like to make the research as 'user friendly' as possible. Unfortunately, such research inevitably includes the undertaking and completion of questionnaires, however WCB staff are looking towards methods of their completion that will reflect the capacity of individual organisations e.g. completion via telephone interviews, one to one meetings and so on.

The Research project will be co-ordinated by Emma John - 'Information and Research Officer' who will be more than happy to discuss the programme and best methods of consultation with organisations. For further details contact Emma on Cardiff 029 20 473954.

## Awareness Trainers Needed for WCB.

WCB is looking for volunteer trainers and assistants to help us deliver our OCN-accredited Awareness Training in Visual Impairment to a wide variety of groups including care workers, leisure centre staff and police officers.

The aim of our training is to let people know the facts about visual impairment. Our team of volunteers provide basic awareness training

(eye conditions, the practical and emotional effects of sight loss etc.) and, if required, special modules tailored for the particular group e.g. residential homes, care workers, arts organisations and leisure centres. We even deliver training to student Police Officers and Welsh Prison Service staff.

All our trainers are visually impaired and the degree or type of your sight condition is not important. It helps if you are confident and enjoy group activities. If you have any experience of speaking in public or dealing with groups, this would be a great help, plus you must be ready to learn the material included in the sessions. But most of all you must want to communicate the facts about visual impairment - not so much your own personal experiences but an objective and factual account that can convey a positive message.

Each trainer works with a sighted assistant. To be a sighted assistant you must be able to drive and have the use of your own vehicle, as part of your role is to drive the trainer to and from the training venues. During the session the assistant supports the visually impaired trainer as much as is necessary. As well as setting up equipment, handing out information, writing up flipcharts, they lead/oversee some of the practical and role play exercises. You will need to be calm and efficient and to respond to the trainer's needs but be willing to remain in the background if necessary. We try to match people who are congenial and we find then that each trainer and assistant usually work out their own way of co-operating to their own satisfaction.

WCB provide an induction and training for volunteers, and pay a mileage rate and train fares for travel and expenses for any necessary meals or overnight stays.

If you think that you would like to be a W.C.B. volunteer or you know someone who might, please contact Nicola Lewis on 029 2047 3954 or email [nicola@wcb-ccd.org.uk](mailto:nicola@wcb-ccd.org.uk) for more information.

# Tourism and Holidays when you are visually impaired.

Each issue of Roundup will be looking at a topic of relevance to VI people, and, as this is the time of year when many people start to think about holidays or days out, we thought we would provide some information about this.

## Research into understanding the experiences of tourists who are visually impaired.

Despite efforts by some tourism academics, there is a dearth of research focusing on the experiences of visually impaired people in tourism which has meant that disability research remains on the fringes of tourism scholarship. The industry has also been more concerned with the "Tourist Gaze", finding it difficult to look beyond "seeing" to form the tourism experience. For the past two and a half years, Vicky Richards a PhD student at the University Wales Institute, Cardiff, Welsh Centre for Tourism Research, through her research, has been involved in raising the profile of visually impaired people.

The research is concerned with addressing how visually impaired people's participation can be better understood by exploring the barriers to full participation and to understand the impact tourism experiences can have on an individual's emotional and physical well-being, self-esteem, self-confidence, and identity. The research explores their embodied experiences in an attempt to discover the meaning and significance of tourism in their lives. This focuses on how people participate using their other senses and the extent to which this sensory information and "feelings" evoke a fuller experience that is other than a visual one.

Vicky is a qualified rehabilitation officer with 17 years of experience working for and with organisations for visually impaired people and individuals themselves. It is this background that has influenced how she has undertaken the research. Her approach is to make the research empowering for the participants so that they guide and inform her but to also capture the individuality of experiences by ensuring that their voices are heard in the research process and findings.

Part One of the study involved working with four visually impaired people's groups at the Cardiff Institute for the Blind. The discussions revealed issues around the individual (emotional, psychological and (in)dependence); societal (lack of awareness by staff, decision makers, stereotypical images) and Environmental (physical access, accessible information and transport). Part two, nearing completion, involved discussions with five families highlighting similar themes as Part One but in addition it also focused on how individuals with low vision connected with the tourism environment e.g. on a beach, at an attraction, at a restaurant, at the airport etc. As a result of working with families, themes also emerged around family priorities and family relationships.

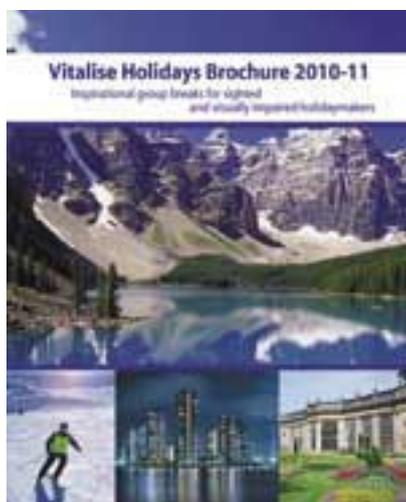
It is hoped that this research will challenge the stereotypes held by tourism academia and the industry which characterise visually impaired people as a homogenous group with the same needs and aspirations as others. The research is due to be completed in September 2010, and Roundup will let you know what conclusions were reached.

# Holiday Contacts.

There are several organisations which claim to specialise in meeting the needs of visually impaired people, so we are including information on some which may be of interest. We would be interested to hear of readers' experiences – have you used any of the companies, and if so, would you recommend them? Do you feel that they address the needs of visually impaired travellers, and what are the gaps in the market?

## Vitalise

Vitalise Holidays specialises in providing group holidays in the UK and worldwide for visually impaired adults, who are supported throughout their holiday by Vitalise sighted guides. The holidays are grouped into five categories:



- Leisure, where the emphasis is on relaxation.
- Sightseeing to places of interest in the UK or abroad.
- Interest, based around a particular subject or hobby such as dancing.
- Activity, based on a sport or outdoor pursuit such as skiing.
- Adventure, to a country such as Japan, where the culture and facilities are different from the UK.

For more information, telephone 0845 330 0149 or go to the website, [www.vitalise.org.uk](http://www.vitalise.org.uk).

## Royal National College for the Blind.

RNC run adventure holidays for young people aged 13-17 and activities include quad biking, rock climbing, art and design, music

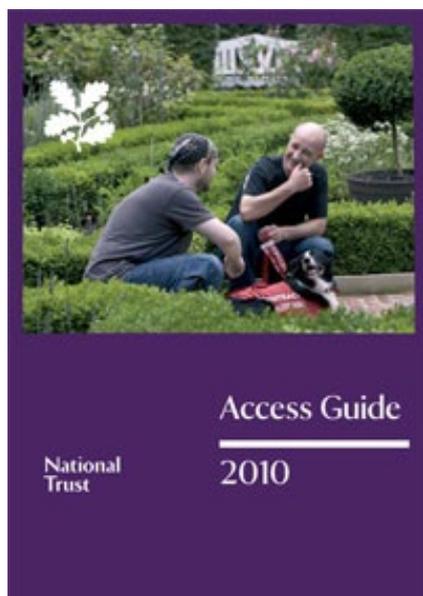
technology, radio broadcasting, dance and drama. For the less energetic, computer games and website design sessions are available. For details and bookings telephone 01432 376 622 or visit [www.rncb.ac.uk/summeractivities](http://www.rncb.ac.uk/summeractivities).

## Vision Hotels

Action for Blind People runs four Vision Hotels, in Windermere, Bognor Regis, Weston-Super-Mare and Teignmouth, which particularly welcome visually impaired guests and have excellent facilities for Guide Dogs. The hotels are fully accessible, with staff trained in visual impairment awareness. For more information, visit the website [www.actionforblindpeople.org.uk/hotels/](http://www.actionforblindpeople.org.uk/hotels/), or telephone the individual hotel:

- Cliffden Hotel, Teignmouth - 01626 770052
- Lauriston Hotel, Weston-super-Mare - 01934 620758
- The Russell Hotel, Bognor Regis - 01243 871300
- Windermere Manor Hotel, Windermere - 01539 445801

## The National Trust



For those planning a trip to one of the National Trust's properties, their Access Guide gives full details of the facilities available to disabled visitors, which include braille and large print guides, with sensory information at some sites. It can be ordered in standard or large print by phoning the Trust on 01793 817634, and on CD or tape by phoning 'Sound Talking' 01435 862737. You can also download the Access Guide from the website [www.nationaltrust.org.uk](http://www.nationaltrust.org.uk).

The Trust also operates an 'Admit One' scheme,

where the necessary companion or carer of a disabled visitor is admitted free of charge. For more information, telephone 01793 817634.

## Torch Trust

The Torch Trust organises holidays and retreats in a Christian family atmosphere for visually impaired people. Most holidays are based at the Trust's Holiday and Retreat Centre in Sussex, which is fully accessible, and include breaks based around interests such as crafts and gardening. Some holidays are also held elsewhere in the UK, and in France.

Torch Trust can be contacted on 01273 832282, or visit the website, [www.torchtrust.org](http://www.torchtrust.org) for more information.

## The Jubilee Sailing Trust

Founded in 1977 under the patronage of HRH The Duke of York, the Jubilee Sailing Trust was set up to give disabled people the opportunity to discover the thrill and adventure of offshore tall ship sailing as a member of a mixed ability crew.

The JST operates tall ships, LORD NELSON and TENACIOUS, the only ships of their type in the world that were purpose designed and built to enable mixed ability crews to sail side by side as equals on year round voyages, varying from one-day sailing experiences to longer trips around the UK, Europe, the Canaries and the Caribbean. The facilities aboard the two fully accessible ships represent over 30 years of experience taking people with physical disabilities to sea.

For more information, you can write to the Trust at 12 Hazel Road, Woolston, Southampton, S019 7GA, telephone 023 8044 9138 or go to the website [www.jst.org.uk](http://www.jst.org.uk) to download a brochure.

# Our Local Societies.

If you would like to contact any of the listed societies, please contact Wales Council for the Blind and we'll put you in touch. And if your society isn't listed here, let us know.

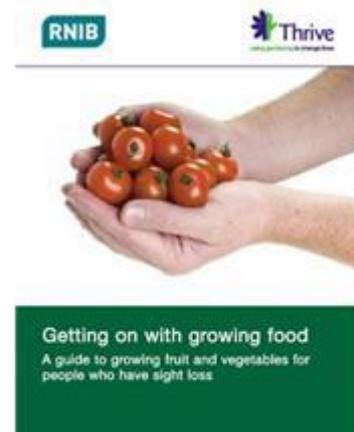
Please note that WCB shall soon be moving to a new address. Our other details shall remain the same, but the address shall be Wales Council for the Blind, 2nd Floor, Hallinans House, 22, Newport Road, Cardiff, CF24 0TD.

Abergele Club for the Blind  
Aberystwyth & District VI Club  
Barry Visually Impaired Persons (CIB)  
Bell Bank Club  
Blackwood VIP Club  
Bridgevis  
Caernarfon VI Club  
Cardiff Institute for the Blind  
Cefn Mawr Blind Club  
Ceredigion Association for the Blind  
Cowbridge VI Group and Gardening (CIB)  
Eyeline Port Talbot  
Friendly Club of the Blind  
Gwent VI Bowling Club  
Insight  
Llandovery & District Blind Association  
Macular Disease Society Cardiff  
Merthyr Eyelights  
Merthyr Institute for the Blind  
Monmouth Club for the VI  
Mynydd Mawr Branch,  
Carmarthenshire Blind Society

North Wales Society for the Blind  
Pembrokeshire Society for the Blind  
Penarth Blind Club (CIB)  
Porthmadoc & Criccieth Blind Society  
Prestatyn VI Club  
Radnorshire Association for the Blind  
Rhondda Blind Society  
Rhuddlan Club for the Blind  
Risca Visual Impairment Group  
Sight Support  
The Bedwas VI Club  
The Deeside Club for the Blind  
The VIPs  
The Vision Club  
Tywi Branch Llandeilo,  
Carmarthenshire Blind Society  
V I Merthyr  
Vision Support  
Visual Impairment Brecon  
Vision Impairment West Glamorgan  
Welshpool & District VI Club

# Growing Food when you have Sight Problems

Thrive, the charity which helps disabled people to enjoy gardening, has produced a new book, 'Getting on with Growing Food' which gives detailed information on how to grow fruit and vegetables when you have sight loss.



The 172-page book, which is available in large print, on Daisy CD, on audio CD, tape and in Braille, covers all aspects of growing food from planning to crop rotation, and includes a year planner. It is the third publication in Thrive's 'Getting on with Gardening' series, and costs £7.50 (£5 for members of the National Blind Gardeners Club).

The other books in the series are 'Getting on with Gardening (1)', which is the essential guide to gardening when you have a visual impairment and covers activities including seed sowing, gardening outside, tools and equipment, raised beds, preparing the ground, planting and watering, and 'Getting on with Gardening (2)' which has information on taking cuttings and potting, container growing, gardening outside, protected growing, pruning, lawns, and pests and diseases.

Thrive also produce a 55 page Gardening Yearbook which is free of charge to partially sighted and visually impaired people.

To order, telephone Thrive on 0118 988 5688, write to The Geoffrey Udall Centre, Beech Hill, Reading, Berkshire, RG7 2AT, or visit the website, <http://www.thrive.org.uk/products/publications/gardening-when-you-have-a-disability.aspx>.

# Free Audio Publications from 'Sound Talking'

Sound Talking, which is the commercial arm of National Talking Newspapers and Magazines, provides publications from M&S, Argos, Sainsbury's and Waitrose in audio CD, free of charge.

The publications include the Argos Catalogue and 'Your M&S' quarterly magazine. The Sainsbury's and M&S publications are also available on audio tape. For details, and to place your order, go the website, <http://www.soundtalking.co.uk/request-publications.html>, or telephone 01435 862737.



# Forthcoming Events

The following events may be of interest to visually impaired people in Wales. Don't forget to let us know if you would like us to include an event in your area.

## Action for Blind People – Mobile Sight Loss Information Service

The Mobile Sight Loss resource vehicles enable visitors to try for themselves the latest technology and gadgets to improve daily life for blind and partially sighted people, and will be at the following sites in Wales over the next few months:

- \* 25-26 May, Swansea
- \* 29 June – 1 July, North Wales
- \* 17-18 August, Merthyr Tydfil
- \* 19 August, Breconshire

Full details of the venues were still to be confirmed at the time of writing, but once agreed, will be available on the AFBP website, [www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk), or from ringing 0303 123 9999.

## Sight Village 2010

The Queen Alexandra College 'Sight Village' returns to Birmingham's New Bingley Hall from 13 – 15 July 2010. This is a chance for visually impaired people, their families and professionals working in the sector to find out at first hand about the latest technology, products and support services available to people who are blind or partially-sighted. The exhibitors are commercial companies and voluntary organisations from throughout the world, and admission is free.

# South East Wales.

Health Fair gives advice to minority ethnic communities in South Wales



A Minority Ethnic Communities Health Fair was held on Thursday 21st January, 2010 at City Hall, Cardiff.

The event, which was a huge success, was jointly organised by:

- \* Sight Support (previously Gwent Association for the Blind)
- \* Ethnic Minority Communities First (Cardiff)

- \* MEWN Cymru
- \* BAWSO Women's Aid and
- \* Voluntary Action Cardiff.

Nearly 350 people from a diverse range of minority communities and groups, attended.

The aim of the Health Fair was to raise awareness and contribute to the development of health and wellbeing lifestyles of members of the minority ethnic communities. The first of its kind, in Wales, it addressed health needs specific to minority ethnic communities and encouraged people to look after their own health, both mental and physical. The Fair also provided practical advice on choosing a healthier lifestyle.

Highly respected speakers gave presentations on many different health conditions predominant in people of minority ethnic communities such as, heart disease, stroke, diabetes, diabetic retinopathy and glaucoma.

In addition to the talks there were 38 exhibitors in attendance including both statutory and

voluntary organizations.

An eye screening service was carried out by Andrew Feyi-Waboso (Consultant Ophthalmologist) at Royal Gwent Hospital and his Eye Clinic Team. Mr Waboso and his team consulted with 67 people and some serious conditions were detected. This was a very popular service with people queuing for the "Eye Examinations."

Also in attendance; The Diabetes Mobile Unit (supplied free of charge by Silver Star UK) was located outside City Hall. The unit tests glucose levels to establish whether individuals are at risk of diabetes. They also measure height and weight, calculate body mass index (BMI), body fat mass, muscle mass and metabolic age. The diabetes mobile unit tested 84 people.

The Stroke Association undertook blood pressure checks and again this service was very popular.

During the afternoon session

workshops were held on:

- \* Reiki
- \* Indian Head Massage
- \* Reflexology
- \* Laughter
- \* Yoga
- \* Tango Dance

All of the above activities focused on encouraging the benefits of relaxation and exercise.

This event would not have been possible without the help and support of staff from the five organisations, together with the invaluable help from volunteers, all from diverse ethnic communities. We are very grateful for their support.

If you would further information about this event or any future events, please contact Nirmala Pisavadia at Sight Support (previously Gwent Association for the Blind), telephone 01495 763650 or email [Nirmala@gwentblind.org](mailto:Nirmala@gwentblind.org)

# West Wales.

## ICT Needs in Ceredigion

In the previous edition of Roundup, we reported on a survey of ICT needs carried out by WCB in association with Ceredigion Association for the Blind. As a result, we invited applications for an part-



time ICT Development Officer for Visually Impaired People to cover the Ceredigion area.

A shortlist has been drawn up and the successful applicant will be required to assess people with sight problems within their home, as well as provide help with installation, configuration and training. We are hopeful that the successful applicant will start work in May.

This project is not just about using computers - it concentrates on how people with sight problems gain access to all forms of information, including bank statements and letters. If you think that you would benefit from a visit from our officer, please contact Owen Williams at the WCB office.

## Can the Linnecar Trust Help You?

The Trust exists to give grants to people who are registered blind, and who live in the counties of Ceredigion, Carmarthenshire and Pembrokeshire. Grants have included awards for computer equipment, reading machines, CCTVs, holidays, household equipment and for the relief of financial difficulties.

An application form can be obtained from Wales Council for the Blind.

# North and Mid Wales.

## Shopping Buddies Scheme in Rhyl

Following a successful trial, Denbighshire Voluntary Services Council has launched a 'Shopping Buddies' Service at Sainsbury's in Rhyl. The service operates every Wednesday between 11am and 3pm, when volunteers are available to escort customers and help them with their shopping. The assistance provided might include:

- \* assistance with reading labels
- \* carrying your bags
- \* pushing your trolley

Users of the service are responsible for making their own way to the shop, must respect the scheme's equal opportunities policy, and must handle their own money/credit cards.

If a carer usually brings a person to the shop as a rule, then one idea could be that the carer brings two people along, then one could be helped by a Shopping Buddie. The service is already being used by a number of visually impaired customers. Once at Sainsbury's, just make your way to the customer service desk and request one of the Shopping Buddies.

It is hoped that the hours which the scheme operates will be extended in the future.



# Focus on...

## nystagmus network



### Plugging a wobbly gap

“What does he actually see? Is everything moving? What should I do to help my daughter find her way around new places? Why does she have nystagmus?” These are typical of the questions that families ask when I give talks – as I did in Gwent in December – about what it is like to have nystagmus. I answer those questions as best I can based on my own experience of having nystagmus and on what I’ve learnt from talking to many others over the last 20 years.

The questions highlight a gap in the way statutory services meet people’s information and emotional needs. Hospital staff do their best – and some do

an amazing job – but they rarely have the time families want. And unless medical staff have nystagmus themselves, they will struggle to answer questions about what it’s like to live a life not driving.

Talking to families who have children with nystagmus tends to be a very emotional experience. Sometimes parents are angry at the lack of support they receive in hospitals. Often they feel guilt about why their child has nystagmus. And they’re generally anxious about what the future holds in terms of education, employment and – of course – managing without a car.

That’s where the Nystagmus Network (NN) comes in. We can answer the questions and we know from experience that

there's absolutely no need for nystagmus to ruin anyone's life, no matter how unlikely that may seem to worried parents.

If you have nystagmus your eyes move involuntarily – or “wobble” – so you can't see very well. You might nod your head or hold it at an angle which other people find strange. Nystagmus gets worse when you're tired or stressed. You almost certainly won't be able to drive. School, work, sport -- even simple social activities like meeting friends for a meal or a drink – are more difficult in a hundred little ways than for someone with normal sight.

We don't know how many people have nystagmus. One recent study put it as high as 2.4 per thousand if you include every form of the condition. Others estimate that it's more likely one in a thousand or two thousand. Taking the figure of one in 1,000 means 60,000 people in the UK have nystagmus. Put that in a Welsh context and that's more than the population of Barry – the biggest town in Wales. Or about three times the population of

Llandudno.

You can develop nystagmus in infancy, in which case you'll have poor vision all your life, or as an adult. We don't know exactly why nystagmus develops in some babies, but it is often linked with albinism, childhood cataracts, damage to the optic nerve and many other eye conditions. If you develop nystagmus in adulthood, it's usually linked to illnesses like multiple sclerosis (MS), stroke or a head injury for example.

There is no cure yet. But the Nystagmus Network -- working with professionals -- can do a lot to help people with nystagmus lead happy, fulfilled lives. Many of the challenges associated with nystagmus – as with other eye conditions – are due to ignorance about the condition and a sense of isolation: “Why am I the only person I know who has nystagmus?” is a typical question.

NN tackles these challenges through education and training and through our newsletter, publications and telephone

helpline. On our website forum ([www.nystagmusnet.org](http://www.nystagmusnet.org)) you can read about experiences of nystagmus, write about your own and ask others for advice. Here's what one 25 year old said on her first visit: "I've had nystagmus since birth but never thought until now to browse Google and see who else out there has the condition(!). It's amazing reading stories by others with the same condition and thinking 'that's so true!'"

In the NN newsletter people with nystagmus write about education, employment, bullying and above all about how nystagmus – for all its annoying and sometimes unpredictable quirks -- is not the end of the world. Our publications include practical guidance about school, work and transport, as well as a story book and audio CD for children with nystagmus.

We provide training for teachers, hospital eye departments, social workers

and other professionals. We explain what living with nystagmus means and help them develop better ways of supporting people with the condition. We make sure, for example, that teachers understand the null point and what that means for where a child should sit in a classroom.

Sometimes it's hard to believe what a difference simply answering families' questions can make. But it does, as this comment from one parent to NN shows: "My 2 month old son was diagnosed last week with nystagmus and your article was a big help. We walked away from the hospital with very little information except that he could be blind, and will probably never drive!! It was a comfort to read that he will more than likely lead a very normal life. Thank you!"

John Sanders, development manager, Nystagmus Network

# WCB's Link Officers

The staff at WCB are points of contact for our member organisations and have been allocated regions by county. If you have a query or would like to tell us about your organisation's activities, please contact the relevant officer below on 029 20 473954.

Phil Stevens: Carmarthenshire, Rhondda Cynon Taff, Cardiff, Vale of Glamorgan, Bridgend, Neath Port Talbot, Swansea.

Rebecca Phillips: Powys, Monmouthshire, Blaenau-Gwent.

Nicola Lewis: Torfaen, Newport, Caerphilly.

Richard Bowers: Denbighshire, Flintshire, Wreccsam.

Dilwyn Price: Merthyr Tydfil, Gwynedd, Anglesey, Conwy.

Owen Williams: Pembrokeshire, Ceredigion.

Wales Council for the Blind,  
Shand House,  
20, Newport Road,  
Cardiff, CF24 0DB.

Tel: 029 20 473 954  
Email: [staff@wcb-ccd.org.uk](mailto:staff@wcb-ccd.org.uk)  
Web: [www.wcb-ccd.org.uk](http://www.wcb-ccd.org.uk)