

Wales Council of the Blind Roundup

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No. 26



Vision Support's Prestatyn Sight Loss Centre

Cllr. Bob Murray, Mayor of Prestatyn and Meliden, opens Vision Support's new Sight Loss Centre. It is open to the public from 10 am to 3 pm, Monday to Thursday. The centre provides information, advice and support to vision impaired people in the area.

Telephone 01745 472558

In this issue:

**A look at Community Voice projects
Focus on The Macular Society**

Supplements:

Storm WCB

Perspectif: Eye Clinic Liaison Officers

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EDITORIAL.

Welcome to the latest edition of Roundup. This edition has two supplements: Perspectif and WCB Storm.

WCB sees impartial signposting as an important function that helps both our partners and, importantly, people who face circumstances where they need support to help them with anything from participation to emotional problems. Perspectif is an online portal to a wide range of such support and we shall be showcasing a different aspect of it in an ongoing series of supplements. This first one focuses on Eye Clinic Liaison Officers and we hear from two of RNIB's officers about the service generally and in Powys, and a features an exciting new high street service in Newport.

The second supplement is the latest news from the WCB Storm young adults' project. Megan John and Mared Jarman have been engaged on this project since June last year and two events have been held. You can read reports on those [here](#).

Also included is a questionnaire that seeks your views on independent living. The Welsh Government published its Framework for Action on Independent Living in 2013 and is currently seeking to refresh it with further input from disabled people. Many people would not have heard of this document, but it is used by Welsh Government to guide policy and planning ensuring that decisions have disabled people in mind. We would be grateful if you could complete this to make sure the Framework is fit for purpose.

- Richard Bowers.

WCB Roundup is published quarterly by **Wales Council of the Blind**, 2nd Floor, Hallinans House, 22 Newport Road, Cardiff CF24 0DB. Tel: 029 20 473954.
Email: richard@wcb-ccd.org.uk.

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Advertisers will reach a readership of individuals with sight loss, optometrists, ophthalmologists, rehabilitation officers, social workers, and organisations working for blind, partially sighted and disabled people.

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WCB NEWS.

Your Voice: a Shared Vision.

West Wales Regional Forum

Thursday, 23rd March 2017 at Carmarthenshire Association of Voluntary Services, 18 Queen St, Carmarthen SA31 1JT. 11am - 2pm.

You are invited to a free event focusing on health, social care and wellbeing in your area. A free lunch and refreshments will be provided. Travel can be reimbursed if required.

We want to hear your views, experiences, solutions and ways forward on social care, transport, accessing your high street shops and the Framework for Action on Independent Living.

Contact WCB's Engagement Officer, Rebecca Phillips, on 029 20 473954 or email bec@wcb-ccd.org.uk if you would like to attend.

South East Wales Regional Forum

Thursday, 30th March 2017 at Newport Salvation Army, 1 Hill Street, Newport NP20 4EP. 11am - 2pm.

You are invited to a free event focusing on health, social care and wellbeing in your area. A free lunch and

refreshments will be provided. Travel can be reimbursed if required.

We want to hear your views, experiences, solutions and ways forward on social care, transport and the Framework for Action on Independent Living.

Contact WCB's Engagement Officer, Rebecca Phillips, on 029 20 473954 or email bec@wcb-ccd.org.uk if you would like to attend.

WCB Storm Event.

Ein Llais Ein Storm, Our Voice Our Storm is WCB's new young adult project. Roundup now features a supplement on this project. The first is included in this edition.

Contact us on:

Facebook: www.facebook.com/StormWCB

Twitter: [@StormWCB](https://twitter.com/StormWCB)

E-mail: mared@wcb-ccd.org.uk or megan@wcb-ccd.org.uk

Telephone: 029 20 473 954

Next issue: Direct Payments

In the next issue we will be looking at Direct Payments, where local authorities pay individuals directly in order for them to purchase their own care. We would like to hear about your experiences of claiming direct payments in Wales: was it straightforward, what problems did you encounter? Are you aware of the system and if you receive the payments, how have they helped you? Please send any comments and stories to us at WCB by April 30th.

Community Voice

“Decision makers do not always look to hear our voices but we voice them anyway. As a unit they listen more. BCDF have given us that unit and the platform for getting involved.”

The Big Lottery Fund’s ‘Community Voice’ project is aimed at giving thousands of people in Welsh communities a stronger voice in local decision making. Grants totalling £11 million were allocated to ten Community Voluntary Councils (CVCs) across Wales in December 2012.

Leading up to this, the Lottery invited county voluntary councils to bid for grants for projects that engage citizens (particularly those from excluded groups) with decision-making structures in their regions. Each bidding CVC would invite smaller bids from groups in their area to participate in the scheme, forming a portfolio in each area. Successful portfolios bids focused their work on groups that are often marginalised and find it hard to engage with the organisations that affect their lives: single parents, homeless people, social housing residents, stroke survivors, residents of specific areas, LGBT people and disabled people. An important element to the scheme is that groups connect with each other to share resources, opportunities to engage, and training. The portfolios run for 3 or 4 years and some are still running.

Not all portfolio bids were successful. However, the successful proposals cover large parts of Wales such as Anglesey and Conwy, Gwent, Pembrokeshire and Bridgend, and a wide range of communities of interest. In this article, we have gathered some reports from various portfolios with the intention of seeing how disabled people have been engaged.

First of all, let's have a glance at some of the projects led by disabled people's groups which address barriers faced by disabled people.

- In Cardiff and the Vale, Disabled People in Action are leading a project with refugees and asylum seekers.
- North Wales Deaf Association run a project to improve services by making them more accessible to deaf and hard of hearing people and to raise awareness of disabling barriers.
- Disability Wales led a project in Pembrokeshire to improve understanding amongst disabled people of the commissioning processes that determine the services they receive.
- The Forget Me Not project in Newport, led by Newport People's First, worked to enable adults with learning disabilities.
- The Minority Ethnic Communities Project, led by Sight Cymru in Monmouthshire, was aimed at encouraging blind and partially sighted people from ME communities to take up services that improve daily living.
- In RCT, Cardiff Vale and Valleys for the Blind led the 'Wanting to be Heard' project to empower disabled people and give them the skills for self-advocacy.

There are many more projects: around eighty were funded throughout Wales, overseen by ten lead organisations. It's a huge, ambitious scheme, but what did it do? Here are some reports from around the country.

Sharing our lives, planning together.

Bridgend Coalition of Disabled People (BCDP), in partnership with Wales Council of the Blind and Disability Wales, runs a county-wide Community Voice project administered by Bridgend Association of Voluntary Organisations. This report gives an overview of their successes.

Sharing our lives, planning together project provides opportunities for disabled people to gain knowledge, confidence and an ability to speak out about issues affecting them and others. This is achieved through the delivery of our information training programmes, coffee afternoons; train the trainer sessions and social networking events. We aim to ensure the accessibility of venues and materials in order to meet individual requirements and be inclusive to all. Our project aims to open links for people to become involved with local service providers and be able to speak face to face with professionals regarding key issues and how they can get involved.

“I enjoy speaking to service providers such as those in the Council and contributing towards consultations. The Coffee Afternoons allow us to do this and have fun. My confidence and knowledge on my rights and how to tackle certain issues has grown and I feel that is largely due to regularly attending the Coffee Afternoons BCDP provide.”

As part of this project BCDP host monthly coffee mornings to act as a support group where our members can network with each other and service providers. The coffee afternoons act as a platform for members to get together and voice their views and experiences with the aim to make Bridgend County Borough a more accessible place to live and work. They meet to talk over various issues but in particular to discuss what is - and what is not - working well for disabled

people in Bridgend, and how disabled people can work together with public services to achieve a more accessible society. The aim of these discussions is to empower and inspire change in public services to increase independent living for disabled people. These meetings increase confidence and social skills as members are able to have fun and meet new people.

Our coffee afternoons have received 100% positive feedback with members showing an increase in confidence when conversing with a larger group and when putting their point across to service providers. Members have also explained that they feel more supported; better informed regarding services within their community that can help them and have greater assertiveness when helping other disabled people since joining the group. We have seen an 80% increase in people attending regularly in the past year.

“BCDP’s information days have been so beneficial and have really helped me understand the real issues that disabled people face. I saw myself up there (on stage) and I am looking forward to working with the group to ensure things change.”

This project provides free training events chosen specifically by Disabled People with the aim to increase knowledge, skills and confidence when engaging and influencing services within our members’ community. The events have also increased the knowledge of both disabled people and service providers to understand the needs of disabled people and how they can change their services to become more inclusive.

“I found this training package very interesting. The trainers were really very good and had a great way of putting information across in a way which was easy to understand. I

am more confident to pass on my knowledge to others and understand my rights and how to use them.”

2016 saw BCDP focus on the Train the Trainer side of the project in order to enhance the knowledge and upskill our members so they are confident and equipped to deliver training and advice to others. Our Training information days have included Mental Health Awareness; Welfare Rights Event; Understanding the Social Services and Wellbeing Act; Accessing Transportation around Bridgend.

BCDP aim to have skilled, trained representatives of disabled people working alongside local authority officers and public/private and third sector agencies in planning and commissioning services. In order to ensure this was successful BCDP, along with partners Wales Council of the Blind and Disability Wales, designed and developed a bespoke training package specifically for our members to complete.

The package covered disability equality training as well as covering the rights disabled people are entitled to and how they can get involved in their community and use them. From feedback received the Project Training Days achieved 100% completion from all participants with all recording an increase in their level of understanding into topics delivered. A total of 89% of participants recorded an increase in their confidence when approaching service providers and services within their community following this training.

The Project Development Officer along with the Chair, Trustees and BCDP members attend events in areas across the Borough to promote the work of BCDP and provide help to anyone facing barriers. They arrange and distribute information to local community centres, GP's Surgeries, schools and colleges, and they offer presentations to groups or organisations on disability issues. They ensure

communication with key support organisations is maintained to ensure members are receiving the best support, catered to their individual requirements.

The project has so far increased membership from 42 members to 101 members and increased the service providers membership from 9 to 62. It has enabled the group to respond to six consultations (Orange Wallet Scheme, Blue Badge Charges, Disabled People Manifesto, Social Services and Wellbeing Act, AMBU Strategic Equality Health Plan, Bus and Community Transport Services). It has enrolled four of its members onto the Bridgend Equality Forum and three onto the DWP Advisory Panel. The coalition has advised a panel of Council members in the annual Equalities Committee Meeting on the issues that face Disabled People in Bridgend. It has contributed the design of the Hate Crime Logo to be commissioned across South Wales.

That report was submitted by Cathy Rogers on behalf of the Bridgend Coalition of Disabled People. A key to the success of this project has been using the grant to employ Cathy in post to function as as the glue to ensure the group is coordinated and expanded.

Planning Together.

In Swansea, the Healthy Cities portfolio has a project called 'Planning Together' run by SAIL, the Swansea Association for Independent Living. This project gets disabled people trained in the skills necessary to engage with service providers and make a meaningful contribution to the way that services are delivered. Firstly, Charlotte Davies, Portfolio Coordinator, tells us about Healthy Cities.

Swansea's Healthy Cities Community Voice portfolio works to enable citizens to have greater involvement in policy and decision making within Health and Social Care Services. In

Swansea, the Community Voice is made up of a portfolio of 7 different third sector organisations namely: BME Voice, Community Champions (working with people with a learning disability), Community Green Spaces, Dyma Ni (Carers Transition Project), Patient Carer Participation Groups, Planning Together (promoting independence amongst disabled people) and Your Opinion Matters (working with domestic abuse survivors).

The Community Champions, led by Swansea People First, recruited 10 people with learning disabilities as Community Champions to involve and inspire others to express their views and effect change in service provision in a creative, accessible way. Although the project has now ended, the champions continue to actively contribute in meetings across the local authority and health board to ensure the voice of those with learning disabilities are heard in those bodies making decisions which directly affect their lives.

Dyma Ni is a Carers centre project aimed at supporting parent carers of young adults aged 14 - 25 with a disability to influence how services which affect them are delivered. A number of beneficiaries have completed a Peer Advocacy training course and have undertaken training in Independent Advocacy Level 2. There is ongoing attendance at the following planning and strategy groups: ASD Strategy Group, Co-production Implementation Group, Disability Strategy Group and Children and Young People Provider Forum.

The work of the projects has been diverse, each with their own set of challenges and achievements. It would seem that across the board progress has been slower than initially hoped for. Key staff members change position due to restructuring just as they seem to be understanding the need for coproduction, meaning that it feels work has to start from scratch. However, with the new Health and Social care Act enshrining coproduction in law, it seems that the local

authority and health board are now taking note of the opportunity to work with these knowledgeable groups, meaning that the legacy of the Community Voice will live on well beyond its funding.

Planning Together. Swansea Association for Independent Living (SAIL CIC) was formed in 2007. A group of disabled people decided to take control of their own lives, greater independence and in particular Direct Payments.

Andrew Hubbard, then chairman of SAIL, said 'It seems too simple to say but we would like to have some ownership and control of our own lives'. SAIL members wanted to be more active and share responsibility for services all disabled people use such as Direct Payments.

The great chance came with the Community Voice Portfolio application to the Big Lottery. SAIL set out to be the change they look for in building equality of opportunity. Current support services disabled people use did not involve disabled people in their commissioning processes or planning, delivery and evaluation. SAIL's project is called: 'Planning Together'.

The main work of SAIL was to build the self-confidence of our members, in order to sit down with the decision makers and main managers and have a conversation about services we find improve our lives.

What services work and what do not. We set out to save money on costly retro-fits that occur when equal access had not been considered without the expert knowledge of service users.

SAIL is now in the fourth and final year of the project. Our project is successful in the fact that the working together aspect became enshrined in law in Wales in the Social

Services and Well Being Act 2016. Co-production is the foundation of the act.

We now co-produce:

- agenda items for meetings.
- changed start time of meetings so more disabled people can attend.
- Co-production in employing personal assistants.
- Advertising jobs for support workers on the County web site.
- A budget for expenses and lunch for disabled people who volunteer to attend the Direct Payment group.

Being valued and co-producing services at an early stage is key to the success that SAIL is beginning to realise. Co-production in this way will carry on long after Community Voice portfolio funding has finished.

Co-creating Healthy Change.

The Cardiff and the Vale portfolio includes a number of disability organisations. Here's an update from Mary Duckett at C3SC.

Co-Creating Healthy Change has entered the third quarter of its fourth year. As the projects wind to a close the success of each partner has been clear and substantial.

By empowering community members through training and information-sharing sessions, giving them the opportunity to review health care services and a platform to voice their opinions direct to service providers, CCHC aims to help the local Health Board improve its services across Cardiff and the Vale of Glamorgan.

Five of the partners remain on the project with their work in its final phases.

Action for Caerau and Ely (ACE) Community

Ambassadors: *'The Ambassador Project is about providing information and raising awareness of the many diverse health and wellbeing services available to the Ely and Caerau communities.'*

The ACE Community Ambassadors are currently working on the sustainability of their project, allowing the group to continue to work without the intervention and support of the Communities First staff. They are currently engaged with the Local Health Board on the development of a new health centre based in the local area. Their insight has been sought out by a number of different organisations including Alzheimer's Society, the Welsh Ambulance Service and Public Health Wales.

Mental Health: CAVAMH is currently supporting Cardiff University to engage medical students with its service users allowing for first-hand learning and experiences to occur, as well as the support of research into mental health services. CAVAMH have also distributed over 400 questionnaires to mental health service users and carers, this has involved working in collaboration with the National Centre for Mental Health at Cardiff University, who have supported with collating feedback. A small group of service users have also drafted a letter to the Local Mental Health Partnership Board, again with the support of the National Centre for Mental Health.

Diverse Cymru: Diverse Cymru have continued to run and develop a number of events, focus groups and training sessions aimed at linking service users with members of the Local Health Board, third sector organisations and private sector companies. Diverse Cymru have also supported

Cardiff Metropolitan University and Cardiff University degree and masters programmes by facilitating and supporting service user engagement.

Hafal: Staff at Hafal's Mental Health Carers project, have successfully run numerous events including the summers '*Big Carers Tea Break Event*' which saw Mark Drakeford AM and Kevin Brennan MP listening to the concerns of service users and carers. Hafal have also supported carers onto partnership panels and forums with the aim being the sustainable engagement after the project comes to an end. Hafal are looking to plan more events for this summer before their project comes to an end, as well as continue with their various drop-ins in hospitals and GP surgeries across Cardiff and the Vale.

Media Academy Cardiff (MAC): The young people who are currently engaged with MAC's Visual Voice project are currently creating items that have been utilised by the BBC on their Welsh language healthy eating media. MAC have also been engaged with the University of South Wales and the Welsh Government to discuss the wellbeing of young people in education. The MAC young people will also be looking to create a short audio-visual work of the success of the Co-creating Healthy Change programme.

Voices – Anglesey

This report comes from the Anglesey project, 'Voices', where the North Wales Deaf Association and the North Wales Advice and Advocacy Association run projects to work with deaf and hard of hearing people and individuals with a learning disability respectively.

'Voices' started in 2013 and has 8 communities of interest including homeless communities, deaf communities, those with learning difficulties and long-term limiting illnesses and

older people. The project has worked mostly with Anglesey County Council and other local public services to try and change the way that they engage with people who are classed as hard to engage, whilst at the same time working with participants to develop tools, training and the skills and confidence to talk to public service providers.

To date successes include:

- Producing information, documents and consultations in easy read or more accessible versions including British Sign Language. 'Visit Anglesey' is the first County Council tourism site in Wales to have BSL as an option and our Single Point of Access project offers SKYPE access for those with hearing problems.
- Producing upskilling toolkits for project beneficiaries to develop skills in identifying an issue, collecting information and negotiating with service providers. The toolbox was funded by Welsh Government and is currently being adapted by Public Health Wales as an online resource.
- Developing a Building Communities Model for engaging people within the communities that they live in as opposed to their community of interest. This model is a positive discussion about where the person lives, how they use local services and what skills and knowledge they have as community members before looking at what priorities they have for the future in terms of services and activities. The model has been accepted as best practice for engaging communities by Anglesey Council and the Public Service Board and has been presented to the Welsh Government Housing Strategy group.

One Voice – Helping disabled people have their voices heard!

This report comes from Merthyr Tydfil, where the project has engaged groups such as Visual Impairment Merthyr (VIM) in improving access and services.

“One Voice is key in helping us to speak out to the Council about the way services don’t meet our needs. I’m glad I’m part of it.”

One Voice came to fruition back in 2012. At that time, Merthyr Tydfil’s reputation as a valley community was not deemed to be good. TV programmes and news articles frequently demonised the town, blighting it with bad publicity, focussing on some of its most deprived communities, negative issues associated with benefits, sickness and other negative stories. One Voice was established as part of the larger consortium in response to the bad press, as it highlighted local need for a disability project where people across Merthyr who identified themselves as having a disability or a health need, could be supported to work together, solving problems, breaking down barriers, and aiming to bring about overall positive change in the area.

To date, One Voice has enabled and empowered over 100 participants to become involved in the project, which supports individuals and groups alike. One Voice has been successful in raising awareness about specific disabilities, and supports mechanisms to bring local services and people together co productively, to improve services delivered locally, and enables them to have their voices heard at forum meetings.

There have been many successes over the lifespan of the project, from establishing safe walkways in the local Castle car park in conjunction with the Highways Team at the local

Council, and in conjunction with a local group VIM (Visual Impairment Merthyr), user friendly and appropriate walkways were established at St Fagans Museum in Cardiff. Plans have also been submitted for a safe pelican crossing to be installed at the local Cyfarthfa Retail Park. All of the above have involved several meetings of One Voice participants and local service providers to discuss issues, and find ways to overcome them. One Voice has a productive working relationship with Heads of Services for Merthyr Tydfil Council and local support groups and organisations, and is often approached to undertake consultation on local issues affecting disabled people.

One Voice provides equalities training to the Senior Leadership Team at Merthyr Tydfil Borough Council, and in delivering this, is continually consolidating the positive working relationships with the leaders, ensuring that local services continually meet need, and are fit for purpose.

Participants feel that involvement in One Voice has made a significant difference to their everyday lives. One lady who attends a local support group, Café Cwtch, for parents and carers of children with additional needs stated “without One Voice’s involvement in helping me access vital information post diagnosis of my son’s Autism, I would have felt lost and not known where to turn for help.”

These are just a few examples. One Voice is fully committed to empowering and enabling all who have a disability in Merthyr Tydfil to get involved and work together to make Merthyr a more tolerant, disability friendly town, where everyone’s needs are met, and that people’s views are listened to and that they included at all times, in helping to shape the vital services that they require.

See it My Way.

The Valleys Voices portfolio covers Blaenau Gwent and Caerphilly and is overseen by Gwent Association of Voluntary Organisations. See It My Way is a Sight Cymru project in the portfolio that enables people with sight loss to have a say in matters which affect them. It is managed by Project Officer, Judith Parry. Judith tells us of the most recent developments.

A group for people with sight loss and their carers in Blaenu Gwent has recently started to move towards self-management. It now has a committee, drawn from amongst the membership, which works with other members to plan and provide the monthly sessions. This Visually Impaired Persons' (VIP) group meets every third Friday of the month between 10am and 12 noon for a mixture of chat, refreshments and information.

They receive visits from a variety of speakers from time to time, such as local refuse wardens, community connectors and most recently a representative from Arriva Trains Wales. A gentleman from the local library service is also a regular attendee, who helps with access to talking books, and strong links exist between the group and the Rehabilitation Officers for VI who cover the area.

The Caerphilly See It My Way group now meets every 6 weeks, usually in the central library, having increased the frequency from once per quarter. They use this time to discuss matters which are of concern to them and seek to move towards solutions, as well as having an opportunity to socialise.

They recently received a visit from the local police to discuss issues such as pavement parking. Other key speakers over the past year have been Nathan Foy, from Guide Dogs, who

gave them information about tactile paving and a representative from the Welsh Ambulance Trust who took a number of their comments on board.

One key issue this Caerphilly based group continues to try to address is the matter of access to public transport for people with sight loss, especially buses.

'Wanting to be heard'

Interlink runs the 'Changing Lives, Changing Communities' project in Rhondda Cynon Taff. Cardiff Institute for the Blind delivers a project in this portfolio. This report was taken from the RCT Newsletter.

Aims: Improve service delivery for blind/partially sighted people in RCT by mapping where services are deficient or do not meet the needs.

Identify and work with key partners and other disability groups to empower service users, through training, to speak up and have an effective voice in their communities.

Provide training and support to blind and partially sighted people to become advocates, so that the standards and delivery of services in their localities better meets the needs of people with sight loss.

Laura, a vision impaired volunteer, has been with us since the beginning of June. She has not been able to work due to medical reasons but had expressed an interest in helping out with the office and taking part in the various activities. Since beginning with us she has: co-written the Contact Line folder, undertaken admin, joined the Steering Group and taken part in the Finding Your Feet course. I also discussed with Laura the possibility of delivering awareness raising sessions in schools and fundraising projects. Since then Laura has been

to two schools with her guide dog raising awareness of vision impairment.

‘I’ve enjoyed volunteering; I needed to get out of the house. It’s nice knowing that if I have a bad day I’m not committed to coming in.’

CIB has worked with local councillors to promote issues of travelling by train for vision impaired people. Councillor Geraint Hopkins, Chair of RCT Equality Forum, and Councillor Steve Powderhill, Treforest, undertook a blindfolded journey from Cardiff Central to Pontypridd where they changed trains to go onto Porth. The aim of this journey was to highlight and demonstrate the difficulties faced by the vision impaired community of RCT. The biggest obstacle CIB wanted to draw attention to was the lack of audio announcements on both stations and trains, which places vision impaired people at a terrible disadvantage and, at times, danger. During the journey the councillors also identified an issue with the distance between the train and the platforms; an issue we have brought up on many occasions. The journey was followed by a feedback event in the Heritage Park Hotel, Porth where the councillors were gracious enough to provide a detailed description of their experience and our members were invited to give their personal experiences of past train journeys. This was extremely positive for the councillors who have already taken the issues further by contacting Arriva trains and passing their views onto Nick Anthony, the AM of RCT, who in turn has passed it on to the Welsh Assembly. They now hope that continued campaigning will bring positive change.

Many of the Community Voice portfolio projects continue, and shall continue after the Lottery-funded period closes, so if you would like to find out more about them, contact your local County Voluntary Council for the currently-running schemes.

Macular Society.

The leading charity supporting people with the most common cause of sight loss in Wales is celebrating its 30th anniversary.

The Macular Society, which is the national charity for anyone affected by central vision loss, has 22,000 members across the UK and has grown rapidly over the last few years.

Age-related macular degeneration (AMD) is the biggest cause of sight loss in the UK, currently affecting more than 29,000 people in Wales.

The Macular Society started work in Wales in 2015, thanks to funding from The Big Lottery Fund's People and Places grant. The funding was awarded so the Society could expand its services in the country over a three-year period. It will allow 10 new support groups to be set up, in addition to the existing network of 16 groups in the country. The charity aims to grow awareness of macular disease as well as the volunteer-led services offered by the Society, such as group support and telephone befriending, which help those with macular conditions gain confidence and learn new skills.

Diana Williams, aged 62, is just one of the many people who has benefited from the support of the Macular Society. When Diana woke up one morning, aged 49, she was unable to see properly and was quickly forced to give up driving, her job and her home. But she was determined the condition would not mean she would give up on life - and quickly began looking at focusing on what she could do, instead of what she could not.

"I'd always been in the caring profession and had always looked after all sorts of people, and had seen and heard of so many things that people go through but you never think any of it will happen to you, and a few years later exactly the same thing happened to my right eye.

"I went to an optician, was sent to the hospital and they said it was age-related macular degeneration. I was told that there was nothing I could do about it. I knew nothing about it and I didn't know where to turn, and I'd never heard of the condition."

She added: "When I was diagnosed I felt lost for words. I left the hospital not knowing anything about it and not quite believing that I'd had it permanently and that there was nothing I could do about it. But eventually I realised that if I did have it permanently then I should just get on with life and focus on what I can do and not what I can't do."

Soon after her diagnosis Diana found the Macular Society online and has been in contact with them ever since.

"They were a great help when I was diagnosed, they explained a lot of things to me and within a year I started to attend a support group in Swansea."

Since the Society was formed by a small group of patients and eye consultants 30 years ago, it has helped hundreds of thousands of people living with macular conditions and invested millions of pounds in medical research.

The Society's mission in 1987 was the same as it is today, to find a cure for macular disease in the future and provide rehabilitation and support now.

For more information contact the Macular Society helpline on 0300 30 30 111.

Macular Society Services.

Macular Society helpline

Being diagnosed with macular disease can leave you and your family feeling isolated and uncertain about the future. But, there is no need to face macular disease alone; the Macular Society specialist helpline team provide free information, guidance and advice to anyone affected by central vision loss whether it's you, a friend or a family member.

Cost: Calls cost the same as standard rate calls to landline 01 or 02 numbers and will be included as part of any inclusive call minutes or discount schemes

Postcode: SP10 9AD

Email: help@macularsociety.org

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/helpline>

Befriending

The Macular Society's befrienders make regular calls and enjoy chatting. You choose what you want to talk about - it could be about macular disease, your favourite hobbies or TV programmes, or just the weather! Particularly suitable for people unable to join a support group. The Society aims to find you a befriender who is local and shares your interests, experiences or type of macular disease.

Postcode: SP10 9AD

Email: help@macularsociety.org.

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/telephone-befriending>

Skype Groups

Skype groups give members the opportunity to talk to others affected by macular disease, without leaving home. People of all ages can take part in video or voice only calls.

Postcode: SP10 9AD

Email: stella.black@macularsociety.org

Weblink: <https://www.macularsociety.org/local-support-groups>

Treatment buddies

The Macular Society can put you in touch with a Treatment Buddy who has already had treatment, for information and reassurance. If you are experiencing visual hallucinations (Charles Bonnet Syndrome) due to sight loss there is a buddy service where you can talk to someone who has also experienced visual hallucinations for information and reassurance.

Postcode: SP10 9AD

Email: help@macularsociety.org.

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/buddies>

Macular Society local support groups

The Macular Society has local self-help support groups across the UK. The groups vary in size and style but all offer invaluable practical and emotional support to people with macular disease from people with macular disease. A number of them (in Wales) are listed below. If you are interested in being part of a group but there isn't one in your area, please contact them to let them know.

Email: info@macularsociety.org

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups>

Swansea

Club for people with macular degeneration in Swansea. Meets at the Grand Theatre from 11.30 am to 12.30 pm on the first Saturday of alternate months (January, March etc).

Postcode: SA1 3QJ

Telephone: 01792 401450

Weblink: <https://www.macularsociety.org/groups/swansea-support-group>

Llangefni

Group supporting people with macular degeneration. Meets on 2nd Friday of each month in Canolfan Ebeneser, Bridge Street, Llangefni.

Postcode: LL77 7LR

Telephone: 01248 353604

Weblink: <http://www.macularsociety.org/How-we-help/Local-support-groups/local-group-pages/llangefni-support-group>

Bangor

Support group for people with macular disease. Meets on the 3rd Wednesday of every month at Quaker House, Dean Street, Bangor. 11am-1pm.

Postcode: LL57 1UR

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/bangor-town-north-wales-support-group>

Blaenau Ffestiniog

Support group for people with macular disease meets on 2nd Thursday of every month, 1-3pm. Gwesty Ty Gorsaf Hotel, 1 High Street, Blaenau Ffestiniog.

Postcode: LL41 3ES

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/blaenau-ffestiniog-support-group>

Pwllheli

Support group for people with macular disease. Meets 2nd Friday of every month.

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/pwllheli-support-group>

Wrexham

Support group for people with macular disease. Meets on the third Thursday of the month, between 1.30-3.30pm at AVOW, 21 Egerton Street, Wrexham.

Postcode: LL11 1LW

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/wrexham-support-group>

Bridgend

Support group for people with macular disease at Evergreen Hall, Angel Street, Bridgend, CF31 4AD. Meets on the first Friday of the month from 10 am to 12pm.

Postcode: CF31 4AD

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/bridgend-support-group>

Cardiff

Support group for people with macular disease. Meets at CIB monthly on the last Friday of the month. 10.30am - 12.30pm. Cardiff Institute for the Blind, Jones Court, Womanby Street, Cardiff CF10 1BR.

Postcode: CF10 1BR

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/cardiff-support-group>

Dolgellau

Support group for people with macular disease. Meets in the Gallery Room, St. Mary's Church, Dolgellau.

Postcode: LL40 1AD

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/dolgellau-support-group>

Llandudno

Support group for people with Macular disease. Meets monthly, on first Monday of the month 10.30am - 12.30pm. Criag Y Don Community Centre, Queens Road, Llandudno, LL30 1TE.

Postcode: LL30 1TE

Telephone: 0300 3030 111

Weblink: <https://www.macularsociety.org/groups/llandudno-support-group>

Conwy

Meets on the first Monday of the month from 10.30 to 12.00 at Craig y Don Community Centre.

Telephone: 01248 680135

Abergele

Meets on 3rd Monday in the month at Abergele hospital.

Postcode: LL22 8DP

Email: hazel.aspey@wales.nhs.uk

Weblink: <https://www.macularsociety.org/groups/abergele-support-group>

Brecon

The group meets on the last Monday of every month. Venue: Brecon Theatre, Canal Wharf, Brecon. Time: 10.30am to 12.30pm. Contact Macular Society Regional Manager, Adele Francis.

Postcode: LD3 7EW

Telephone: 01639 843236 / 07494 468007

Ystradgynlais

The group meets every month on the second Tuesday of the month. Venue: Adelina Patti Day Room, Ystradgynlais Community Hospital, Glanrhyd Road, Swansea SA9 1AU.

Time: 10.30am - 12.30pm. Contact Macular Society Regional Manager, Adele Francis.

Postcode: SA9 1AU

Telephone: 01639 843236 / 07494 468007

ACROSS THE SECTOR.

CIB awarded lottery funding

Congratulations to Cardiff Institute for the Blind, which has been awarded £500,000 by the Big Lottery Fund as part of their 'People and Places' programme. The funding will be used to help people with sight loss engage with their local communities and participate more in activities, sports and leisure interests.

Vision Impaired West Glamorgan AGM

The Annual General Meeting of Vision Impaired West Glamorgan will be held at 12.30 pm on 15th March at Swansea Civic Centre. The meeting is open to vision impaired people living in the City and County of Swansea and the County Borough of Neath Port Talbot. It is an opportunity to hear about the work of the organisation, ask questions, and talk about plans for the future.

There are also vacancies on the committee for people wanting to help improve the lives of people with sight loss. For more information, contact Andrea Gordon on 07581 507575.

CONSULTATIONS.

Welsh Government.

Details of all WG consultations can be found on their website, <http://wales.gov.uk/consultations>. The following may be of particular interest:

- Reforming local government: Resilient and renewed (closes 11 April)
- Guidance on handling individual cases to protect children and adults at risk (closes 25 April)

If you would like a consultation document in a different format, email the document title and the preferred format to CustomerHelp@wales.gsi.gov.uk or call 029 2082 3683.

Give your views on treatments.

The National Institute for Health and Care Excellence (NICE) is the organisation that tells care services such as hospitals, in England and Wales, how they can improve health and social care. In 2017 they're intending to rewrite the guidelines for age-related macular degeneration, cataracts and glaucoma, and RNIB is giving people with these conditions a chance to give their views on all aspects of their treatment. This could cover waiting times, provision of information or treatment.

To give your views, visit RNIB's website, <http://www.rnib.org.uk/living-amd-cataracts-or-glaucoma-we-want-hear-you> and leave your contact details.

OPPORTUNITIES.

Audio described tours of National Museum Cardiff

As reported in the last edition of Roundup, the National Museum Cardiff is running regular audio described tours for vision impaired people. The next event will be on Thursday 6th April and it is a chance to explore specimens from the Clore Discovery Centre, handling items from the collection including skulls, teeth, fossils and much more! Spaces are limited, so advance booking is essential. To book, please contact 029 2057 3240.

RNIB's Connect Project

RNIB Connect is a growing community of blind and partially sighted people and their families, friends, carers and supporters. It is where people can connect with others for peer support and social interaction and find the information and inspiration they need to get on with their lives.

It aims to encourage people who are blind or partially sighted to take part in what is going on locally or further afield, whether it's face to face, online or on the telephone.

The Connect team can also help organise events, groups or activities that would enhance the lives of people who are blind or partially sighted.

By getting involved you can get in touch with other blind and partially sighted people in your local community and have the

opportunity to contribute your own skills and knowledge to help and inspire others.

If you would like to know more about getting involved please contact

Eleanor Rothwell (North Wales):

Mobile: 07702821915

Landline: 02920 8253 18565

Email: eleanor.rothwell@rnib.org.uk

Write: Jones Court, Womanby Street, Cardiff, CF10 1BR.

Glenys Hughes (South Wales):

Landline: 02920 828500

Email: glenys.hughes@rnib.org.uk

Write: Jones Court, Womanby Street, Cardiff, CF10 1BR.

You can also join Connect by calling free on 0303 1234 555. You will receive a monthly newsletter and fortnightly e-bulletins as well access to online and telephone support and information.

PUBLICATIONS AND RESOURCES

Eye health awareness in BME communities in Wales

The results of a project that aimed to increase awareness of eye health and primary eye health care to people from at risk in black and minority ethnic (BME) communities in Wales have been published.

The project was commissioned by Public Health Wales and resourced by RNIB Cymru, Sight Cymru, Cardiff University School of Optometry and Vision Sciences. To find out more and read the full report, visit the RNIB Cymru website www.rnib.org.uk

Effect of a Home Visit-Based Low Vision Rehabilitation Intervention on Visual Function Outcomes

Findings from this trial to examine the effectiveness of home visit-based rehabilitation on visual function, wellbeing and health have been published. It was undertaken by a team at Cardiff University with assistance from Sight Cymru. It is available at

<http://iovs.arvojournals.org/article.aspx?articleid=2592947>

Best Practice Guides for social services professionals and housing providers

Action on Hearing Loss Cymru and RNIB Cymru have produced two new guides aimed at helping social service professionals and housing providers communicate better with people who have sensory loss. The documents were launched by the Welsh Government's Minister for Social Services and Public Health at an event in the Senedd in Cardiff Bay.

The guides are based on the experiences of vision impaired, deaf and deafblind people when accessing social services and housing in Wales. You can find out more and download the guides (in English and Welsh) on the Action on Hearing Loss Cymru website <https://www.actiononhearingloss.org.uk/about-us/wales/campaigns-wales/supporting-people-with-sensory-loss.aspx>.

Target Sports Guide

British Blind Sport (BBS) has launched a new education resource, 'A Guide To Visually Impaired Target Sports: Archery and Shooting'. It has been designed to educate the coaching and club network to ensure a greater knowledge of vi archery and shooting and help enhance the opportunities for more people with sight loss to take part in these exhilarating sports.

You can read the guide on the 'Education' section of the BBS website, <http://www.britishblindsport.org.uk>. This archery and shooting guide is the latest in a range of educational resources produced by BBS, covering sports such as swimming, athletics and football, which can also be found on this site.

New 'Northwick Bear' story for children with nystagmus

Northwick bear is the leading character in a series of stories which help children to understand the eye condition nystagmus. Both Northwick and his young owner have the condition, and their latest story is about problems which children with nystagmus experience in the playground.

The story, 'As far as the eye can see', is available on the Northwick website, <http://www.northwickbear.com/stories.html>, where you can also download the other stories.

“Don’t Ask Me, Ask the Dog”

Mike Brace's new book continues his autobiography from the moment when Mike was featured on “This Is Your Life” in 1981 and finishes just after his involvement with the Olympic and Paralympic London 2012 bid and the organising Committee.

Here’s an extract to whet your appetite:

When Eamonn Andrews greeted me outside Bush House, the home of the BBC’s World Service, and said those immortal words:

“Mike Brace, sportsman and social worker, “this is your life”, I was filled with a mix of emotions. My first reaction was one of surprise and disbelief, and even suspicion, i.e. was it really Eamonn or a friend trying to be funny and putting on an Irish accent? Then, confirmation came from Brian Johnston whom I was there to meet, so it must be true!

After the shock wore off and we were on our way to the studio to record the programme, I also had another thought, I was only 31 and appearing on “this is Your Life”, was that it then? Had I done everything that I was going to do with my life?

I thought back on the day I had just had prior to being grabbed for “This is Your Life”. The day had been a bit hectic and of course I did not have any inkling of what was to come later. When you are an ordinary individual you never expect or dream that something like “This is Your Life” will ever involve you! Looking back after the event I should have smelt a rat.

On the previous Monday I received a phone call from my friend Robbie, who was the Metro blind cricket team’s Captain, to say that he now had to work on the following Wednesday when Metro were due to have their Cricket AGM. I offered to Chair the meeting but he was very insistent that he wanted to be there and that the meeting was cancelled. I remember putting the phone down and thinking, the guys are going to be really hacked off with the meeting being cancelled, just because Robbie couldn’t make it. A few minutes later the phone rang again, and on answering it, I found that it was Brian Johnston, the broadcaster, cricket commentator and Metro’s President. He was asking if I could by any chance help him out by doing an interview about blind cricket for the World Service of the BBC? He said that he knew it was short notice but was I free on this coming Wednesday evening? I, like the idiot I am, said, “that’s really spooky, until about 3 minutes ago I would have had to say no, but my Club’s cricket meeting has just been cancelled so I am now free”.

Brian went on to say that we might have a bite to eat afterwards and tactfully suggested that perhaps I should wear something a bit smarter than my usual social worker's uniform of jeans and jumper! He then astounded me by saying he would send a car for me. I say I was astounded, as anyone who worked with the World Service in those days, knew that they had no budget for things like cars, and barely had enough money to make the programmes!

I still didn't suspect anything; well you wouldn't, would you?

Part 2 of Mike Brace's autobiography, 'Don't Ask Me, Ask the Dog', is available in E format from Amazon in Kindle and also in a print version from Amazon.

Power for Life.

Western Power Distribution (WPD) operates the electricity distribution network in the Midlands, South Wales and the South West. Put simply, our role is to ensure the power network of poles and pylons, cables, wires and substations – the infrastructure that we all rely upon to live our lives to the full – delivers electricity to our homes and businesses around the clock.

Power cut? Call our emergency number 0800 6783 105

Sometimes power cuts can happen for reasons beyond our control. During a power cut we are able to help.

We know it can be particularly worrying if you rely on electricity for medical equipment or if you are elderly, very ill or disabled. If you depend on electricity for a reason such as using a nebuliser, a kidney dialysis machine, an oxygen machine, a ventilator – or any other reason – you should register with us.

WPD provides a FREE Priority Service Register, which helps us to identify customers who may need a little extra help during a power cut.

If you join our FREE Priority Service Register we can:

- Give you a direct number to call in the event of a power cut so you can get straight through to us.
- Agree a password with you before we visit you, so you feel safe.
- Provide special help, if needed, through the RVS (Royal Voluntary Service) or British Red Cross.
- Ring and tell you about planned interruptions to your electricity supply.
- Keep you as informed as possible in the event of an unplanned power cut.

To join, call **0800 9177 953**, or visit our website
www.westernpower.co.uk

EVENTS.

North Wales Alliance Showcase Event

The North Wales Vision Alliance (Vision Support, North Wales Society for the Blind, RNIB Cymru and Wales Council of the Blind) is running an exhibition and information day at Venue Cymru, Llandudno, on Tuesday 16th May. There shall be over 20 local and national exhibitors including a craft fair and various suppliers of technological aids and equipment.

Sighted guides are available as well as transport from parts of North Wales. If you would like to attend, please contact Marian for your free ticket on 01248 353604. Pre-booking essential, so don't miss out!

Inherited Eye Disease Patient Day

On Wednesday 15th March from 5 to 8.30 pm, the Cardiff School of Optometry and Vision Sciences will host an event to look at ophthalmic genetics. There shall be information stands and a question and answer session on "Living with Inherited Eye Disease". Email JenkinsS33@cardiff.ac.uk or telephone 02920 876784 to book a place.

Have a Go Activity Weekend

The Royal National College for the Blind (RNC) in Hereford is organising a free activity day for vision impaired people aged 13-17 years on 11th/12th March.

It's an opportunity to try activities such as sports, performance and cooking, make new friends and find out about life for students at RNC. Parents are also invited, and will be able to take a tour of the College and ask questions. For more information and to book a place, visit the RNC website, <http://www.rnc.ac.uk/news/events> or telephone 01432 376 621.

VICTA Activity Weekend

VICTA is organising a residential break for vision impaired young people aged 14-17 years at Royal National College for the Blind in Hereford from 10th - 13th April.

The event is a great opportunity to try out a range of indoor and outdoor activities, and to socialise and make new friends. There is a charge of £40, which covers accommodation, all meals and activities. For more information and to book a place, visit the VICTA website <http://www.victa.org.uk/youth-activity-rnc/>. The closing date for applications is 7th March.

Struggling with sight loss?

Would you like to talk to someone about coping with your sight loss better? Would you like to meet people in the same situation as you? Would you like to talk about how your sight loss affects you?

If so, Sight Cymru would like to invite you to a two day event which we hope will improve your wellbeing and state of mind. This is your opportunity to access help and advice and to ask any questions you may have.

The venue is the Memo Arts Centre, Gladstone Road, Barry CF62 8NA, and the dates are Wednesday 22nd and Wednesday 29th March, from 10.30am – 2.30pm. The events are free and include lunch. For more information and to book a place, please ring 01495 763650 and ask to speak to Emma Richards.

RNIB's Online Today

RNIB Cymru's Online Today team will be making regular visits to libraries in Fishguard, Pembroke, Tenby, Carmarthen and Llanelli in 2017, helping people with sensory loss gain and develop skills that allow them to use technology and the internet with confidence. Details are as follows:

- Fishguard Library Drop-in Sessions: the fourth Tuesday of every month until 27/06/2017. 3 x 45 minute sessions- 10am, 11am and 12 noon, that need to be pre-booked direct with the library on 01437 776638.
- Pembroke Dock Library Drop-in Sessions: the third Thursday of every month until 15/06/2017, 3 x 45 minute sessions- 10am, 11am, 12 noon, that need to be pre-booked direct with the library on 01437 775825.
- Tenby Library Drop-in Sessions: the first Tuesday of every month until 06/06/2017, 3 x 45 minute sessions- 10am, 11am and 12 noon, that need to be pre-booked direct with the library on 01834 843934.
- Carmarthen Library, the third Tuesday of every month until 20/06/17, 3 x 45 minute sessions at 10am, 11am

and 12 noon, to be booked directly with the library on 01267 224824.

- Llanelli Library, the first Thursday of every month until 01/06/17, 3 x 45 minute sessions at 10am, 11am, 12 noon, to be booked directly with the library on 01554 773538.

Visits will also be made to other venues, for the latest information, visit the website <https://www.rnib.org.uk/online-today-event-search>.

New College Worcester

New College Worcester, the residential college for vision impaired young people aged 11 to 19 years, has arranged a programme of events over the next few months:

- Outreach Open Day, 22nd March – for education professionals and parents (£20 per person)
- Applying to University, 5th to 6th April – free event for those thinking of moving to university or higher education in autumn 2018.
- Family Day, 1st May – free event for the families of children with a vision impairment.

To find out more about these events, visit the website <http://www.newcollegeworcester.co.uk/> and look under 'Latest Events', or telephone 01905 763933.

North Wales Mobile Information Unit.

The schedule for March 2017 is:

- Monday 6th, Tan Y Fron, Llandudno (Extra Care) am and Rhos on Sea pm.
- Friday 10th, Prestatyn Library
- Monday 20th, Ysbyty Gwynedd
- Friday 24th Morrisons, Holyhead
- Monday 27th, Llandudno North Shore by Cenotaph
- Friday 31st, Tweedmill, Trefnant

Please check Vision Support's website <http://www.visionsupport.org.uk/> for further details and for later schedules. It is recommended that you ring 01745 338914 to confirm details before travelling.

Wales Council of the Blind & Wales Council for Deaf People

FIVE STAR AWARDS

Are you a person with sensory loss who has experienced good practice from a health service in Wales? If so, the two umbrella organisations for sensory loss in Wales want to hear from you!

Wales Council of the Blind and Wales Council for Deaf People have come together to recognise the healthcare workers and departments who are delivering excellent support and care for people with hearing loss and sight loss. These positive examples will enable us to highlight good practice and, in turn, encourage other practitioners to improve their own service delivery.

The awards will be presented at The Senedd, Cardiff Bay, 3rd May 2017 by Rhun Ap Iorwerth AM, Shadow Cabinet Secretary for Health and Social Care.

We are looking for examples of positive experiences from people with sensory loss about the sensory-loss-specific support they've received from the broad spectrum of health services in Wales, such as from GPs, optometrists, audiology departments and hospitals in general.

The five star awards are our celebration of the difference accessible healthcare can make and where health board services are delivered in a way that works to the satisfaction of everyone involved, improves patient experience and customer satisfaction and serves as an excellent role model for others to emulate.

Please contact us for a nomination form on 02920 473954 or email bec@wcb-ccd.org.uk

Deadline for all nominations: Friday 7th April 2017

Smell gas?

Staying safe in six easy steps

If you smell gas in your home or business, we're here to help. Here's what to do.

- 1 Call us immediately on Freephone 0800 111 999. We're available 24 hours a day, 365 days a year and will send out an engineer to make your property safe.
- 2 Turn off all your gas appliances and, if possible, switch off the gas at the meter (unless the meter is in the cellar or basement, in which case don't go in).
- 3 Open windows and doors.
- 4 Don't use any electrical appliances or switch lights on or off.
- 5 Don't smoke or use naked flames.
- 6 If there's a smell of gas in the cellar or basement, please wait outside or with a neighbour.



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