

VALE of GLAMORGAN



BRO MORGANNWG



The newsletter for children and young people with special and particular needs in the Vale of Glamorgan

Spotlight on...Epilepsy **3**

Can you claim DLA? **4**

Half Term Schemes **6** & **7**

Good News... **8**



# WINTER IS HERE!

Hi all, I hope everyone has had a fabulous Christmas and a very happy new year!!! I don't know about everyone else but it doesn't seem that long ago since we re-launched the index. Where has the time gone??

We currently have 279 children registered on the index. We are continuously looking to increase that number to ensure that as many families possible are receiving the information and services available to them.

So we have been busy promoting ourselves along with the Family Information Service (FIS).

Becky (Family Information Service) and I carried out a presentation promoting the Index, at a SENCO meeting back in October. We arranged visits to several schools.

At these visits we explained in depth about the index and FIS and how we could all work together. Some of these schools will now be working towards gaining the FIS School Certificate of Achievement, which is brilliant news.

There are currently 13 schools in the Vale that have achieved this, including our first Welsh school Ysgol Sant Baruc.

The Index is funded by the Welsh Government Families First Grant



It means that these schools actively promote the Family Information Service to parents they come into contact with.

They have the FIS posters and leaflets and Disability Index posters and leaflets on display; FIS staff attend parent events at the school; an article about FIS goes out in the school newsletter and much more.

We are hoping that the special needs schools will work towards gaining the Certificate.

On that note, I would like to say that I am sadly leaving to go on to pastures new but you can still use the same contact details to get in touch should you have any queries. enjoy!

## Rhian Phillips

Disability Index Administrator

**01446 704736**

[disabilityindex@valeofglamorgan.co.uk](mailto:disabilityindex@valeofglamorgan.co.uk)

[www.valeofglamorgan.gov.uk/disabilityindex](http://www.valeofglamorgan.gov.uk/disabilityindex)



## Multisport Minis

### Run in conjunction with Penarth Gymnastics Club.

Thursdays 5pm-6pm at £5 per session.  
Non disabled siblings are very welcome.

New physical activity session for disabled children aged 7 and under.

Taking place at unit 3-6 Tŷ Verlon Industrial Estate, behind New Broad Street Motors in Barry.

Parents must register before attending the sessions so we can gain information about your child leading to a more enjoyable experience.

Penarth gymnastics club have over 30 years of experience of providing gymnastics to disabled people and are now offering a session to under 7's.



For more information please ring Gwyneth Lingard on **02920 703701** or Simon Jones Disability Sport Officer on **01446 704728**

# Spotlight on...Epilepsy

'The medical definition of epilepsy is 'repeated seizures of primary cerebral origin.' This means that there is a tendency to have seizures which originate as a result of a change in electrical activity in the brain.

The word 'repeated' is a key part of the definition, as an isolated seizure does not mean it is epilepsy.

An epileptic seizure results from a sudden electrical discharge in the brain that results in an alteration in sensation, behaviour or consciousness.

Seizures can take many forms because the brain is responsible for such a wide range of functions. Symptoms that occur during a seizure depend on where in the brain this abnormal burst of electrical activity occurs. As a result, there are many different types of seizures. Seizures usually last from a few seconds to a few minutes and stop without any treatment.

## Different types of seizures

Since there are over 40 types of seizures, everyone's epilepsy is unique to them. There are however two main types of seizure; these being generalized seizures and focal seizures.

- **Generalised seizures** affect the whole brain and the person becomes unconscious of their surroundings.
- **Focal seizures** only affect one particular part of the brain. What the seizure looks like depends on what part of the brain it stems from and what it controls. The person can become confused and disorientated but will not normally lose consciousness. If they do however lose consciousness, this means that the focal seizure has progressed and turned into a generalised seizure – more commonly known as bilateral convulsive seizure. For support contact **0800 228 9016** or go to **www.epilepsy-wales.org.uk**

## Young Epilepsy phone app

### Managing epilepsy the smart way

We have developed an innovative, free app that can be tailored to the individual needs of young people, or parents of a child with epilepsy.

The Young Epilepsy app includes an easy to use seizure video function; symptom log; diary and medical prompts; as well as discreetly stored emergency and contact details.

Charts can be created based on the information entered into the diary to help identify potential patterns, and data is downloadable, so sharing with your school, parents or healthcare team is easy.

The app is available for download on iPhone through the app store or Android through the playstore.



Contact Young Epilepsy on **01342 832243**  
 Confidential Epilepsy Helpline:  
**01342 831342** Mon to Fri, 9am - 1pm  
**helpline@youngepilepsy.org.uk**  
 Text us: **07860 023 789**  
 \*information taken from  
**www.youngepilepsy.org.uk**

# Could You Be Claiming Disability Living Allowance?



## Citizens' Advice Bureau – Better Advice, Better Lives (BABL)

As part of the Welsh Government's tackling poverty strategy every Citizen's Advice Bureau in Wales is delivering the Better Advice, Better Lives' project.

Based at the Barry Office, the Cardiff and Vale CAB's dedicated BABL team is striving to reach out to local communities in the Vale.

A key aspect of the project is working closely with the Special Needs Health Visitor in the Vale – Clare Thomas, to offer advice and support to families with disabled children.

For many families the process of applying for Disability Living Allowance for a child can be a daunting prospect; the application is 41 pages and 64 questions.

An appointment with one of our specialist advisers, either in the bureau in Barry or in the client's home, provides specialist advice and expertise in the completion of the application. We also offer further support throughout the appeal process, should it be required.

### What is Disability Living Allowance (DLA)?

DLA is a benefit to help with extra costs if a child under 16 has a disability, illness or health condition severe enough they:

- Need much more looking after than a child of the same age without a disability, or
- Have walking difficulties, or both

### Who can claim DLA for a child?

You can claim DLA for a child, as long as you look after them as a parent, step-parent, guardian, grandparent, and foster-parent or even as an older brother or sister. DLA is tax free and can be claimed even if you work, have savings or other income coming in.

### How is DLA worked out?

There are 2 parts of DLA – Mobility and care. A child can be awarded money for one or both. How much they get is based on how much help they need.

#### Mobility – there are 2 mobility rates.

- Lower Rate at £21 per week for a child aged 5 or over who can walk but needs extra supervision to get around outdoors in unfamiliar places.

- Higher Rate at £55.25 per week for a child aged 3 or over who, because of a physical disability:
  - o Cannot walk at all, or
  - o Can walk, but their ability to walk outdoors is so limited they can be considered virtually unable to walk, or
  - o Can walk but the effort needed could seriously affect their health.

#### Care – there are 3 care rates.

- Lowest rate at £21 per week if a child needs extra care or looking after for some of the day, which can be about an hour.
- Middle rate at £53 per week if a child:
  - o Needs extra looking after several times throughout the day, or
  - o Needs extra looking after more than once a night for about 20 minutes or more, or
  - o Needs extra supervision throughout the day, or
  - o Needs someone to be awake at night to watch over them several times or once for 20 minutes or more.
- Highest rate at £79.15 per week if a child needs help during the day and night.

Contact the BABL Team  
**01446 704993**

# Personal Independence Payment (PIP)

## What you need to know

As of 28th October 2013, the DWP started to reassess some existing DLA claimants. They started to invite individuals living in **Wales**, West Midlands, East Midlands and East Anglia to claim PIP if:

- They received information about a change in care or mobility needs on or after 28th October;
- Their fixed term award is due to expire on or after 17th March 2014;
- Children turned 16 years old on or after 7th October 2013 (unless they have been awarded DLA under the Special Rules for terminally ill people); or

- An individual chooses to claim PIP instead of DLA.

The postcode map [www.gov.uk/government/publications/pip-postcode-map-uk](http://www.gov.uk/government/publications/pip-postcode-map-uk) for this area can be found in the PIP toolkit.

Alongside the phased introduction of reassessment activity, new claims to PIP will continue to be taken across Great Britain.

\*Please find enclosed a further information guide to PIP.

## Afasic

Afasic is the UK charity representing children and young people with speech, language and communication needs, working for their inclusion in society and offering support to their parents and carers.

Do you have concerns about your child's Speech and Language? If so please come along to our parent/carer support group.

Barry YMCA – The Hub  
The Jenner Room  
Court Road, Barry  
Vale of Glamorgan  
CF63 4EE

Wednesday 29th January 2014 from 10am-12pm.  
Telephone: **029 2046 5854**  
[www.afasiccymru.org.uk](http://www.afasiccymru.org.uk)

## Cerebra's Sleep Service

**Sleep disturbance is often a problem for families who have children with a neurological condition or brain injury.**

Cerebra's sleep team can support carers and help with a wide range of sleep issues including:

- Bedwetting
- Good sleep hygiene
- Nightmare
- Night terrors
- Anxiety at night
- Night-waking
- Sleeping alone
- Rhythmic movement disorder
- Biology of sleep
- Melatonin

They can give advice by telephone, post or e-mail and in certain areas they have sleep counsellors who can make home visits.

They can also give talks on sleep related topics to groups of parents or professionals.

Cerebra is a national charity supporting children and young people with neurodevelopmental conditions and brain injury through research, education and direct, on going family support.

To find out more about how they can help visit our website [www.cerebra.org.uk](http://www.cerebra.org.uk).

To find out more, please contact them at [sleep@cerebra.org.uk](mailto:sleep@cerebra.org.uk) or call them on their freephone helpline **0800 328 1159**.



# Half Term Schemes

## Penarth Youth Project's Disability Teen Scheme

October half term Disability Teen Scheme was a brilliant success with lots of young people attending.

Teen Scheme dates for February 2014 are:

- Monday 24 February
- Tuesday 25 February

Disability Teen Scheme caters for young people aged 12-19 years and costs £5 per day.

Mark them in your calendar!

Places are limited and are by referral only and by completion of the Helpful Book.

All Teen Schemes are held at:

Byrd Crescent Community Centre,  
Byrd Crescent, Penarth, Vale of Glamorgan.



Please provide a packed lunch and drinks.  
Contact Tracey Downes

PENARTH YOUTH PROJECT  
'Serving the Vale'  
Unit 3D, Verlon Business Park  
Verlon Close, Barry, Vale of Glamorgan  
CF63 2BE

Telephone: **01446 734088**

Email: **cbcp@penarthyouthproject.org.uk**

Penarth Youth Project's summer 2013 Disability Teen Scheme is made possible by funding provided from the Welsh Government Families First Programme



# Playscheme



The October half term was held at Cadoxton School over 3 days and as luck would have it Halloween fell on the Thursday.

All children took part in a range of spooky activities and a good time was had by all.

64 children and 25 linked in children (children needing 1 to 1 care) registered over the 3 days.

The Play Development Team are currently planning for the February half term scheme. The dates will be the 25th, 26th and 27th February. Venue to be confirmed.



Please check web page for details  
[www.valeofglamorgan.gov.uk/en/enjoying/leisure\\_and\\_activities/play/play\\_scheme/](http://www.valeofglamorgan.gov.uk/en/enjoying/leisure_and_activities/play/play_scheme/)  
Telephone 01446 704809

## Important Information for Parents and Carers

**Specifically tailored services which meet the needs of children and young people with a disability that run in the Vale of Glamorgan include playscheme, teenshcheme and sports based activities.**

All staff have training and experience of working with children with disabilities.

The services are equipped to support individuals with a range of needs from providing nursing care, 1:1 support and adapted activities to enable everyone to participate in a range of activities.

In order for staff to plan activities, staffing levels and the number of spaces available for children and people, children need to be booked onto the scheme. Once sessions are allocated, children need to attend.

Staff understand that there are times when the child cannot attend such as when they are ill. In these situations if you can let the co-ordinator know as soon as possible, it allows the place to be offered to someone else.

It is also important that staff are fully informed about an individual's needs before they attend, by completing information which will be sent out prior to them attending.

This doesn't mean they won't be able to attend, it just means that staff are able to put the necessary things in place to be able to meet each individual's needs.

Thank you

**Ginny Kolmar**  
Families First  
Disability Strand Co-ordinator

## Good News...

# Motion Control Dance Programme

As mentioned in the previous newsletter, Local Motion Dance Company was delighted to be selected for an Understanding Disability Award by the Cardiff and Vale Parents Federation.

The award was for the best local group in recognition of their work in promoting a positive understanding of people with a learning disability.

The aim of the award is to encourage good practice in improving attitudes in the community towards disability.

Take a look at the photos from the ceremony.



Thank you to all our dance members and parents for their continued support, the young volunteers who help out in the sessions and a special thank you to our wonderful teachers Sophie Batey, Sam Griffiths and Sammie Owens for all their hard work and creativity.

We welcome any new members to come and dance with us at Barry YMCA on Thursdays 4.30-5.15pm for ages 5-10 years and 5.30-6.30pm for ages 11-18 years.

For more information please contact Emma Mallam on **07725 038778**

## Vale Youth Speak Up Travel To Lithuania

**In September 2013, Vale Youth Speak Up travelled to Lithuania as part of the Youth In Action Programme.**

6 group members travelled independently and took part in a very busy programme which included arts, crafts, sport and cultural evenings.

The group has expressed that this project enriches their lives as follows:

- 'Knowledge of countries and how they do things'
- 'Helps us to make new friends'
- 'Not be scared of things'
- 'I can go on a plane without my parents'



Vale People First will be working with Tina Simmons from the Youth Service in the very near future, to help us host and facilitate a Welsh Programme, where the countries involved will come to the Vale and experience our culture and share the good practice in our area.

We are looking forward to including all our partners in this initiative.

If you want any more information, please call Liz or Ros on **01446 732926**.



# Saturday & After School Club

## Sessions with Touch Trust



Family Fun at Touch Trust – Touch Trust is offering wonderful opportunities for all to come along and enjoy sessions of enlivenment, relaxation and joy!

Enjoy movement and relaxation sessions for all ages with the most profound disabilities, autism and behaviour that challenges, at our purpose-built spaces in the Wales Millennium Centre, Cardiff.

Whatever age and ability the Touch Trust programme changes lives. We focus on intensive interaction and sensory in a welcoming, happy atmosphere. So come along, relax and have fun with our specially trained session leaders.

We have overhead hoists, full changing facilities, sensory equipment and specialist lighting.

Touch Trust has everything you need for a carefree visit that everyone can enjoy.

\*Saturday sessions\*

\*After School Club\*

\*Group or one to one sessions for any age\*

\*Family sessions for parents and children\*

\*Creative further education activities for 19-25 year olds with profound complex needs\*

### Open Monday to Saturday

Touch Trust is one of eight resident organisations based in Wales Millennium Centre.

We are a pioneering charity providing creative, touch based art movement and dance programmes for individuals affected by autism; behaviour that challenges and profound and multiple disabilities.

Email: [info@touchtrust.co.uk](mailto:info@touchtrust.co.uk)

Website: [www.touchtrust.co.uk](http://www.touchtrust.co.uk)

Tel: **029 2063 5660**

Touch Trust  
Wales Millennium Centre  
Bute Place, Cardiff Bay  
Cardiff  
CF10 5AL

Company No. 3681562

Registered Charity No. 1078995

## Welcome Kirstin Hampton to ABCD Cymru

ABCD Cymru has a new case worker for the Vale of Glamorgan – Kirstin Hampton. ABCD Cymru is committed to providing a free impartial and confidential service to black & minority ethnic disabled and/or chronically ill children and young people.

We have worked with over 400 families from 20 different ethnicities, speaking 30 different languages and dialects.

We work with disabled children, young people and their parents, with all manner of impairments including physical and mental health problems and long term illnesses.

We work closely with other organisations and statutory services in relation to health, education and social services, training and employment.

We are here to help, we care about you and your family needs. If you live in the Vale of Glamorgan and think you could use help from our services, then please get in touch on **029 2025 0055**



# Follow your dreams...



**Follow your dreams is a national charity operating in England and Wales from its Head Office in Church Village near Pontypridd.**

The charity inspires children and young people who have learning disabilities to quite literally... follow their dreams.

Our vision is for children and young people with learning disabilities to recognise their potential, be ambitious and be provided with the opportunities to... follow their dreams.

The charity focuses on children's abilities, growing and developing skills through the delivery of creative and interactive events, dreams and workshops.

For more information on how to access services, see the contact details below.

Follow Your Dreams, has delivered puppet making workshops in Tonteg and Bridgend with Mr Tumble and we have visited the Millennium Stadium with 5 special young people from St Cenydd school Caerphilly and Erw'r Delyn School to meet the Welsh rugby squad ahead of their match against South Africa.



The youngsters were photographed with team members such as our charity patron and Wales Scrum Half, Mike Phillips.

Follow Your Dreams is an expanding charity and relies upon raising funds via Supermarket bucket collections across the UK plus a calendar of events such as Sky Diving,



Marathons and half marathons, Cycle rides, our Annual Golf Event plus sponsored walks and we recently participated in the Mountain Trail Challenge, 20 miles over the Brecon Beacons which raised over £1,400.



We are always looking for brave volunteers to undertake fundraising events for us.

The charity organises a Christmas Party and Valentines event every year which are big fundraisers.

We are setting up 'Community Volunteer Fundraisers' who with our help, will be encouraged to organise local fundraising via a variety of activities from disco's to school fetes and placing collecting pots in shops and stores.

Businesses are encouraged to support the work we undertake by making us their charity of the year, staging golf events, dances etc and helping us to raise awareness via business networking groups especially in South Wales.

## **Some facts that drive our charity onwards:**

- One in every five children born in the UK will have some form of learning disability
- 90% of children with a learning disability have experienced 'bullying'
- Children from poorer families are more likely to have learning disabilities
- Only 6% of people with a learning disability are in paid employment

For further information contact Merv Smith Volunteer and Events Manager.

**01443 218443** or

**[merv.smith@followyourdreams.org.uk](mailto:merv.smith@followyourdreams.org.uk)**

**[www.followyourdreams.org.uk](http://www.followyourdreams.org.uk)**

# Association for the Welfare of Children in Hospital (AWCH) Notice of Dissolution

It is with regret that we have to announce that at AWCH AGM in June 2013, members were forced to vote unanimously for the dissolution of AWCH as no nominations had been received for the positions of retiring Chairman and Hon. Treasurer.

It also had to be agreed that an additional factor was that AWCH's campaigning role had come to its natural conclusion.

The present financial climate makes it virtually impossible to achieve its outstanding objective – a Welsh Government funded specific scheme for reimbursing hospital travelling expenses for children and parents.

A special general meeting will be held to ratify the decision. The AWCH Travel & Emergency Fund will continue to be administered in the interim. In order to carry out these functions and the general winding down of the

association the present Trustees/executive committee members and officers were unanimously re-elected to continue in post until 31st December 2013.

Members were eloquent in praise of the work of executive committee officers and members, who over the past 50 years had done much towards improved conditions for children and young people who need hospital care, and their parents.

Thanks were expressed to AWCH members, friends, and colleagues from other organisations and statutory bodies for their loyal support over the years.

**Caroline Crimp – Chair AWCH**

**Ennis Roberts – Hon. Treasurer AWCH**

## Down's Heart Group



**Down's Heart Group is a national charity supporting families with a member with Down's Syndrome and heart problems.**

47% of babies born with Down's Syndrome will have some form of congenital heart defect. Families are supported from prenatal diagnosis to adulthood. Diagnosis and surgery can be very stressful times for families.

Getting unbiased, accurate information and friendly support from someone who really understands can be invaluable.

DHG provides information through the website, topic noted, email and phone helpline, as well as regular newsletters. Membership is free and families can be matched with others going through similar issues if desired. Bi-annual conferences

provide a fantastic opportunity for families and their youngsters to come together to learn and have fun.

We welcome new membership from family members, professional and those with Down's Syndrome and heart problems. Please see our website [www.dhg.org.uk](http://www.dhg.org.uk) for more information or contact:

**0844 288 4800**

**[info@dhg.org.uk](mailto:info@dhg.org.uk)**

Down's Heart Group

PO Box 4260

Dunstable

LU6 2ZT

# Volunteer for Advocacy Matters (Wales)

**ADVOCACY  
MATTERS**  
(wales)

Advocacy Matters (Wales) is proud to be Advocacy Quality Performance Mark accredited guaranteeing a premier Advocacy Service for all our clients in Wales.

## Can you help someone speak up for their rights?

Volunteer to be a one-to-one Citizen advocate and help people with a learning disability have their say.

For more information please phone Oz Pearson – Operations Manager on

**(029) 2023 3733**

email: [oz@advocacymatterswales.co.uk](mailto:oz@advocacymatterswales.co.uk)

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

## New Guidelines on Managing and Supporting Children with Autism

**The National Institute for Health and Clinical Excellence (NICE) has published new clinical guidelines on the management and support of autism in children and young people.**

According to NICE, recent studies have shown that there are more than half a million people in the UK with an autism spectrum condition and at least one in 100 children is thought to be affected.

The new guideline from the government's health watchdog, Autism: the management of children and young people on the autism spectrum aims to ensure that children and young people with possible autism, and their parents or carers, get appropriate care and support.

## Newsletter Feedback

We are always interested to hear your thoughts and feelings regarding the newsletter. So if you have any suggestions on how we could improve the newsletter or would just simply like to feedback to us.

Please do not hesitate to contact us on one of the following:

Telephone: **01446 704736**

Email: [disabilityindex@valeofglamorgan.gov.uk](mailto:disabilityindex@valeofglamorgan.gov.uk)

[www.valeofglamorgan.gov.uk/disabilityindex](http://www.valeofglamorgan.gov.uk/disabilityindex)

Post: **Disability Index  
Family Information Service  
Dock Office  
Subway Road  
Barry  
Vale of Glamorgan  
CF63 4RT**

