

Spring 2009

contact a family
for families with disabled children

in contact

The Contact a Family newsletter

Wales

Local office

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UK Freephone Helpline
0808 808 3555

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Drummer, Billy Cobham enjoying making music with children at our Autumn drumming workshop

Who to contact



Keith Bowen, Wales Manager

- any matters relating to national policy and campaigning
- linking with other voluntary organisations
- training for professionals

e-mail keith.bowen@cafamily.org.uk

tel. 01792 390203



Katie Barrett-Goode, Enquiries and Group Development Officer

- general or individual enquiries relating to a disabled child
- local group development
- factsheets and publications
- anything to do with the Contact a Family Wales newsletter or mailing list

e-mail katie.barrett-goode@cafamily.org.uk

tel. 029 2039 6624



Jill Bartlett, Development Officer & Family Support Worker

- workshops for parents
- family days
- events and activities
- individual support to families in North Wales

e-mail jill.bartlett@cafamily.org.uk

tel. 01248 670965

End of Volunteer Local Area Representative Scheme in Wales

We are sad to say that, due to lack of funding, this scheme has now come to an end for the foreseeable future. We will be applying for funding in the future to appoint some more volunteers but, in the meantime, we would like to thank all of the volunteers that have dedicated their time and worked so hard for us over the years.

Thank you!

Electronic Newsletter

Due to lack of specific funding for this newsletter, we are planning to cut down our postal mailing list as much as possible with a view to everybody receiving the newsletter electronically by the beginning of 2010. This will have no effect on the information you receive and you will still get notified of Contact a Family events and activities. As well as this, you will also receive updates between newsletters.

To register for this service please send an email from your chosen address titled "**EMAIL NEWSLETTER**" to **katie.barrett-goode@cafamily.org.uk**

In the body of the email, please state your **NAME, POSTAL ADDRESS** and the **COUNTY** you live in.

For more information on this service contact Katie on 029 2039 6624

Workshops

It's been a while since we updated on workshops. Partly because the continuation of the project has been uncertain due to funding. Thankfully, at the 11th hour we have received funding from the Waterloo Foundation. This will secure the post of Workshop Development Officer for a further 3 years.

To update you, we ran some popular workshops last Autumn. The highlight of which must be the Drumming workshop with Billy Cobham held in Galeri, Caernarfon North Wales.

Billy very kindly offered to hold four drumming workshop sessions which were well attended by children of all ages. The children had the



opportunity to play alongside Billy Cobham and the Cuban group Asere. As most of the children had some speech and language difficulties and the Cubans had no English or Welsh the only means of communication was by sound and gesture and this worked very well. The sounds created were fabulous with everyone joining in to the best of their ability. Many thanks to Billy Cobham and Galeri for providing this wonderful experience for the children involved.

Several further workshops were run in Cardiff and Pontypridd on Growing up and sexuality. All were well attended and the feedback very positive with lots of laughter and sharing along the way.

We held a sleep workshop in Newport and would be happy to do so again in your area. If you think there is a need, please get in touch to let me know.

The annual wheelchair training also took place in Glanllyn, Bala, North Wales with families traveling from as

far as Swansea to receive the training and enjoy a fun packed activity weekend.

There are 2 free film showings planned in Theatre Colwyn, Colwyn Bay on March 8th and at Galeri, Caernarfon on March 15th (films to be confirmed). We hope to hold further workshops on Wills and trusts during this Year. Please get in touch if you think there would be some interest in your area.



Family experiences of the Disabled Facilities Grant – a big thank you!

In the last newsletter we invited parents to complete a questionnaire on their experiences of the Disabled Facilities Grant process. The research team are extremely grateful to the 130 parents who returned questionnaires. We found that since the end of the parental means test in 2005, more

people are receiving grants but parents still do not receive enough information about the grant. Long delays between initial enquiries and completion of adaptations are also a common problem. The research report will soon be available to download from the Shelter Cymru and Contact a Family Wales websites.

We will be shortly launching the report at the Senedd – if you would like to come along please register your interest by contacting **Katie Barrett-Goode on 02920 396624 or email: katie.barrett-goode@cafamily.org.uk**

New guide to dealing with bullying: for parents of disabled children

Contact a Family has joined forces with Parentline Plus to produce a new guide about dealing with bullying, for parents of disabled children.

The guide is packed full of information and tips around spotting the signs of bullying, action and strategies you can take as a parent, and your child's rights. The guide was developed from a range of stories and experiences told to us by

parents of disabled children affected by bullying. Their tips and stories are included throughout the guide.

If you would like a copy of the guide or to speak to someone about bullying, please call Contact a



Family's freephone helpline on 0808 808 3555

Alternatively, you can download it from the Contact a Family website at: <http://www.cafamily.org.uk/bullying.pdf>.

Group support from Contact a Family

Do you run or are you thinking about starting a parent support group? If so, Contact a Family can offer you support in a number of different ways.

Firstly, you can contact me, Katie Barrett-Goode, Enquiries and Group Development Officer for information and advice on all issues around starting, running and developing a local parent support group. Whatever your query is, please get in touch and I will do everything I can to help. (contact details inside front cover).

Also, our Group Action Pack guides cover a range of topics of interest to both local and national parent support groups. All the guides can be downloaded free of charge

from the Contact a Family website at:

<http://www.cafamily.org.uk/families/supportinggroups/groupactionpack.html>

If you would prefer paper copies, please send me your name, address and the titles you would like and I will post them out to you.

For Local Groups

- Starting a local parents' group
- Holding an open meeting
- Attracting and keeping members
- Local campaigning
- Professional workers and parent support groups

For Local and National Groups

- Charity registration
- The role of trustees

- Leaflets
- Publicity
- Speaking to the media
- Writing a news release
- Patrons and celebrity support
- Public speaking for parents
- Effective meetings
- Reaching Out to Disabled Parents
- Reaching Out to Black and Minority Ethnic Parents
- Reaching Out to Fathers
- Data protection
- Websites
- Virtual communities
- Meetings via telephone conference
- Fundraising
- Newsletters
- Employing a paid worker
- Child Protection

Contact a Family on Facebook

What is Facebook?

Whilst many of us enjoy physically getting together over a cup of tea to talk and share amongst friends, the internet offers an alternative way to do this. And this might be hugely important if you're isolated or struggle to get out.

By connecting online, millions of people have created "social networks" which is an increasingly important factor in encouraging social action and increasing awareness about important issues,

including issues that might not get attention in the newspapers or TV news. Facebook is one of these sites.

How is Contact a Family involved?

Contact a Family UK has just launched its own group and profile on a range of social networking websites, the most prominent of these at the moment being Facebook. We would now like to help parent groups to do the same.



Facebook

How do I register?

It is free to register and all you need is a valid email address. Visit the website and follow the step by step registration instructions.

What does this mean for Wales?

Facebook is a useful resource for families of disabled children and support groups, not only in the UK but also, more specifically in Wales.

Individual support

By registering as an individual and becoming a "fan" of Contact a Family Wales, you can find out about local groups, events and activities in your area, find likeminded parents to chat with and post messages for other parents. These messages can simply be sharing your own experiences or asking for support and advice from others.

Local Groups

If you run a local support group, Facebook is an excellent place to publicise your group. You can let people know about the work of your group and events you are running along with much more.

Contact a Family information

We will use Facebook to keep you up to date with our work, such as: Workshops and events Campaigning and policy work Newsletter and publications

Becoming a fan

After you have registered on Facebook you can search for Contact a Family Wales in the search bar in the top right hand corner of the screen. Here, you can become a fan of the **Wales** section of the site and post messages, advertise your group, meet other parents etc.

This project is currently in it's infancy and we would encourage you to register and to make the most of this resource which will enable us to build even better links with you.

Contact a Family also has pages on the following social networking sites. For more information on these please get in touch

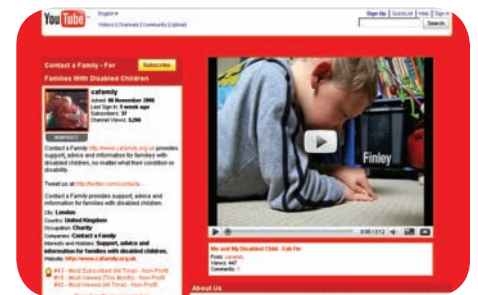
Second Life



Twitter



YouTube



For more information please contact katie.barrett-goode@cafamily.org.uk.

Special Needs Handbook

Need2Know books publish books about life situations and difficulties. Their newest title is *ADHD – The Essential Guide*. This book's easy-to-read style guides parents, teachers and carers through the process of helping a child with this problem, from spotting the symptoms and getting a diagnosis to receiving treatment and finding support. It covers all ages, from small children up to adults.

If you would like any more information please do not hesitate to contact me. You may also be

interested in some of our other titles, *Dyslexia and Other Learning Difficulties*, *Bullying – A Parents Guide*, and (out in October) *Special Educational Needs – A Parents Guide*.

Our books, which cost £8.99, are available from Need2Know by phoning **01733 898103** or emailing **sales@n2kbooks.com**. Details of ADHD and our other titles are on our website: **www.need2knowbooks.co.uk**. The books can also be bought through all good book shops and Amazon.

Carers Contact

Carers Contact is a service provided by Newport City Council and Gwent Association of Voluntary Organisations with the aid of the Carers Grant funding provided by the Welsh Assembly.

It is a centre which is run by two paid workers and a team of volunteers. The centre is open to anyone over the age of 18 years, living in Newport City and caring for, or helping to care for someone. You can call in with no need to make an appointment. The team are willing to help with any problem that is important to you as a Carer or involves your caring role. This could be in the form of information or a listening ear.

They provide information and support to the Carers of Newport on a wide variety of subjects, such as; Carers Services, Carers Assessments, Benefits, Health,

Housing, Respite, Pensions, Aids/ Adaptations, Social Work Services, Support

Also at Carers Contact they.....

- network with other professionals and agencies that work with or are in contact with carers.
- run their own Carers Contact Support Group where they have regular monthly meetings.
- run surgeries in GP Practices across Newport.
- run events at the centre on a monthly basis with guests from other agencies.
- manage events around Newport on Carers Week and Carers Rights Day.

**Newport Market, High Street,
Newport, South Wales
NP20 1DD
Telephone: 01633 258376
Email: carers.contact@
newport.gov.uk**

'My Choices' Project

CAN YOU HELP?

Are you over 16 years and either a parent of a child with complex healthcare needs? Do you live in the UK?

Can you help us be filling in an online booklet about the type of care and services you prefer and were you would like to be looked after in different situations?

If 'yes' please go to: **www.bangor.ac.uk/healthcaresciences/research/mychoices to:**

Find out more information
Fill in a consent form
Fill in the booklet online or download a paper version
Tell us what you think of the booklet

Or, if you want to speak with a member of the team to find out more contact:
Nyree Hulme
Centre for Health Related Research, School of Healthcare Sciences, Bangor University, Ffriddoedd Road, Bangor, LL57 2EF

**Tel. 01248 383150
Email. n.d.hulme@
bangor.ac.uk**

Wellchild Helping Hands project

I work for the National Charity for Sick Children WellChild and we run a programme called Helping Hands where we arrange for teams of volunteers to go into the homes of ill children and over one or two days and make over their bedroom or garden to make it practical and ideal for their condition as many families often do not have the means or the time to do so. As you will have links in your area with ill children through your family workers could you please bear us in mind if you see such a need anywhere as a number of companies have expressed an interest in helping and so we just need to match them up with those families.

We have online applications on our website at www.wellchild.org.uk for anyone that is interested in applying and I have attached an overview of what we do. I would also be happy to send you out some of our leaflets if you think this is something that you could help let people know about? Please contact me if you need any further details.

Sport in Swansea

Swansea Storm wheelchair basketball club is held every Wednesday, 7-8pm at Swansea College. The cost is £2 per person and sports wheelchairs are provided.

The club has been set up in partnership with Swansea Storm, Swansea Council and the Federation of Disability Sport Wales, so all coaches are CRB checked.

Learn to Surf day

The Federation of Disability Sport Wales, in partnership with Swansea Council, the Youth Service and GSD surf are planning a Learn to Surf day for children on the Autistic Spectrum and their families at Caswell Beach in September 2009. The day will be FREE of charge and will consist of small group surf lessons and activities on the beach.

It is a requirement that every child taking part is able to swim a minimum 25m. To assess this we will be offering a number of FREE sessions in the LC2 with the instructors from GSD surf school. These sessions are planned for Easter time next year, and are to assess the participants swimming

ability. They are NOT swimming lessons. Participants should be approx between 8 – 16 years of age.

If you are interested in receiving further information on these sessions and possibly securing a place for your child please contact:

Nicola Rogers
Disability Sports Development Officer, Swansea
01792 635460
Nicola.Rogers@swansea.gov.uk



21 Plus

21 Plus support group for families who have a child with **Down's Syndrome.**

We are a group of parents who meet to exchange information, share the joys and trials of having

a child with Down's Syndrome and have a good chat.

If you are interested in joining us and live in or near Monmouthshire, the Forest of Dean or the surrounding areas.

For more details please contact Victoria (**tel:** 01291 691 472), **email:** vic.andbry@virgin.net or Katharina (**tel:** 01600 711 963), **email:** katharinabarker@gmail.com

Contact a Family Order Form

Name _____ Organisation (if applicable) _____

Email _____ County _____

I would like to receive the newsletter electronically via email

Address _____

Post Code _____ Tel No _____

First copies of factsheets are all free although additional copies are charged at 50p each unless otherwise stated

I would like to be on your mailing list

A number of welsh language factsheets are available on our website www.cafamily.org.uk

When you child has additional needs (£1 per additional copy)	
Benefits and Tax Credits Information Pack (contains a number of factsheets)	
Family Information Pack – siblings – grandparents – fathers	
A Genetic Condition in the Family	
Understanding your child's behaviour	
Holidays Play and Leisure	
Living without a diagnosis	
Transition	
Special Educational Needs – Wales	
Education Maintenance Allowance	
The NHS and caring for a disabled child	
About families with disabled children	
Finding and paying for childcare	
Working and caring for a disabled child	
Aids Equipment and Adaptations	
Disabled Children's Services in England and Wales	
A guide to assessments and services in England and Wales	
Relationships and caring for a disabled child	
Dealing with debt – England and Wales	
The winter guide: help with fuel bills and keeping warm	
Money when your child reaches 16 years of age	
Getting Direct Payments for your disabled child (England and Wales)	
A guide to dealing with bullying: for parents of disabled children	
Sleeping	
Feeding and Eating	
Toilet/Potty Training	
Sex and Relationship Education for young people with physical disabilities: a booklet for teachers	
Growing up, sex and relationships: a booklet to support parents of young disabled people	
Growing up, sex and relationships: a booklet for young disabled people	
General Contact a Family Wales Information leaflets: – workshops – family support service etc.	
Information leaflet: Finding Medical Information on the Internet	

Please return this form to Contact a Family Wales, 33-35 Cathedral Road, Cardiff, CF11 9HB or ring us on 029 2039 6624 or email katie.barrett-goode@cafamily.org.uk

8 029 2039 6624