

contact a family
for families with disabled children

incorporating
The Lady Hoare Trust

in contact



The newsletter of Contact a Family West Midlands
www.cafamily.org.uk/wmids

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Welcome to our summer issue...



By the time you receive this edition of *'in contact'*, the summer will hopefully be well and truly upon us and the summer holidays just around the corner.

Don't forget we can offer advice and support on places to go and things to do during the summer break.

Happy holidays!

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We recently enabled a number of young people and their parent/carers to make hot cross buns, vegetable risotto and pavlova at the Brompton Cookery School, in Shropshire.

Everyone had a great time, and enjoyed eating their meals afterwards.

Our thanks go to the staff of the cookery school...it was a great day!



Fun in the kitchen!

Support “Sound Off for Justice” Campaign Proposed cuts to **Legal Aid**

The Ministry of Justice is proposing to end legal aid in a number of areas which will mean that “the weak and vulnerable will be hardest hit” (Law Society)

Families with disabled children will be directly affected in a number of ways as legal aid will end for

- Clinical negligence cases
- Private family law cases
- Employment and education (other than SEN) law
- Some housing, debt and benefit issues
- Immigration

What can you do?

“Sound Off for Justice” is proposing alternative reforms to the current system which will make savings whilst protecting people’s rights to legal aid.

Just log on to **Soundoffforjustice.org/signourletter** and sign the e-petition

Or ring our helpline on 0808 808 3555

Please sign this petition to protect the future rights of vulnerable people

Whizz-kidz needs your help...

Whizz-kidz, the charity for wheelchair children, is calling on the government to Fast Forward reform of NHS wheelchair provision for disabled children and young people.

An estimated 70,000 children are waiting to receive the mobility equipment that is right for them. This wait often takes months, even years.

In the meantime, children are missing out on their childhood as they’re unable to fully participate in family and school life and keep up with their friends.

This Government has pledged that if Whizz-kidz can raise **100,000 signatures** on one petition it would bring forward a debate in parliament about the need for **Wheelchair Reform**.

So please sign this petition, it could change the lives of disabled children all over the UK.

Go to the ‘news stories’ on Contact a Family website www.cafamily.org.uk and click on the sign at the bottom of the story.

Demystifying DLA

As part of my role as Family Worker, I visit families to support with filling in Disability Living Allowance forms. The application form for DLA is notoriously long, complicated and repetitive, but it's worth it: it could mean up to an extra £125.00* every week, as well as opening the door to other benefits and entitlements. And there are a few things you can do to help the process go more smoothly...

Call the Benefit Enquiry Line on 0800 88 22 00 for an application pack

This will mean that, provided you complete and return the form within six weeks, your award will be backdated to the day you called to request it.

Arrange support as soon as possible

It's usually a good idea to get support completing the form, but most services are very busy and it's best to contact them as soon as possible to make sure you can get an appointment in time to meet the deadline. It's also important to think about anyone who works with your child who might be able to provide a supporting statement and contact them straight away, to give them plenty of time.

Familiarise yourself with the form

It's tempting to put off looking at the form, so set aside some time to go through it, familiarise yourself with the questions and think about how they might apply to your child. You could even make a copy of the form and keep it with you for a week, jotting down ideas as they occur to you.

Keep a diary

Spending a few days making a note of everything you do for your child will make it much easier to answer the questions when you complete the form... and it will probably add up to more than you expect! You can send the diary with your application as evidence.

Give as much information as possible about your child's needs

It can be difficult, but make sure you focus on your child's needs rather than their achievements, give as much detail as possible and try not to play down everything you do for your child. You need to show that your child needs more care and attention than another child the same age.

Send evidence

Send as much supporting evidence as possible. This will support your case and can also help to speed up the application.

Take a photocopy of the form before sending

This is important in case there's a problem and will also help with future applications.

Once you've finished, don't forget to reward yourself: you deserve it! Take some time out for yourself and remember all the really wonderful things about your child (just don't write them down!).

Amy Fox, Family Worker

* current figures @ June 2011

Spotlight on...

We hold a database of many groups, service providers and provisions throughout the West Midlands, and try to feature just some of them in our Newsletter. If you would like us to spread the word about your group, please let Liz know on 0121 415 4624.

'Get together'

Joining families living with autism. This group enables people with a diagnosis of autism/Asperger's and their families to get to know other families. Meet other people with similar interests or hobbies, and build new friendships.

Union Place Baptist Church and Community Centre, Oban Road, Longford, Coventry, CV6 6HH

Every 2nd Wednesday of the month from 5-7pm.

£2 admits one carer and one person with autism. 30p for any additional person.

Call Claire / Kelly on 024 7636 7479 or Visit www.gettogether.uk.com



Beacon Youth Club...

Provides activities for children from 5 up to 18 yrs old, who are blind or partially sighted.

The group meets from 6.30 til 8pm on Wednesdays, and is free. Activities include trips, bowling alley, electronic sports wall, dance mats and much more.

Call the Activity Centre Manager, Caroline Roberts on 01902 880 111 for further details.

Beacon Centre for the Blind
Wolverhampton East, Wolverhampton, WV4 6AZ

Birmingham Dyspraxia Support Group

Meet at Bournville Scout Hut, Laurel Grove, Bournville, B30 1LE.

Future dates are July 6th, September 7th, October 5th, November 2nd and December 7th.

Please call

Ruth Tanner on 07745 266 421 or Rachel Holden on 07724 341 751 for further information.



Telford DCD Group

For local parents of children with Developmental Co-ordination Disorders (DCD) including Dyspraxia. First Friday of every month. Term time only, from 9.45am – 11.30am.



Contact Claire Eaves on 01952 458 018 for further details, or email telforddcd@btinternet.com

The Play Service in Wolverhampton is offering...

Play sessions for children with additional needs.

5-12 yr olds on Tuesdays 5-7pm

5-18 yr olds Wednesdays 5-7pm

at Old Fallings Adventure Playground and Peach Tree Garden.

Den building, pond dipping, arts and crafts, games and much more!!

Call 01902 552 170 for further details.

Little Oaks Children's Club

A club for families with children with special needs.

11am – 1pm every Saturday including school holidays.

Arts, crafts, toys, outdoor play area. Trips planned to local parks and attractions.

50 Providence Rd, Bromsgrove, B61 8EF
01527 877 014

littleoaks.mb66@yahoo.co.uk

Spotlight on...

Emma's fight for her daughter

We were inspired by the story of Emma, who went on the radio; contacted her local newspapers and the local MP, in an attempt to get a wheelchair for her daughter. Amelia, aged 11, had recently been diagnosed with Talus Osteochondral Defect, which had left her in pain, and with limited mobility.

The family were finally successful in getting the wheelchair; had the DLA decision overturned, and an Occupational Therapist visit their home with some positive recommendations.

Emma is truly a credit to her family, and an inspiration to the many families who struggle for their disabled children on a daily basis. Well done Emma!

Charlotte's Tandems...

...have a number of tandems available for disabled or less able people and those with special or additional needs to borrow for **free**.

The borrowers have been mostly children so far, but they welcome applications from all ages. They do not charge for the tandems, but welcome donations and would welcome any spare parts, cycle clothing or merchandise that they could give to the borrowers. Charlotte's Tandems is a charity and its constitution is available on request. (Gift Aid forms are also available).

Tandems are a fun and safe way to get out and about as friends, a couple, family or a group. Charlotte's Tandems have been lucky to get a number of tandems donated, so if you would like to borrow one or have a tandem or components to donate then please contact Alex. They are based in Gloucestershire, UK.

www.charlottestandems.weebly.com

Second hand disability equipment

As many will know, the cost of necessary and vital equipment for our children and young people can often be very expensive. Although some items are available through NHS, some families find themselves finding and funding equipment themselves. There are a number of websites which may be useful to families and there are also a number of charities which may well fund the items too.

www.cheapdisabilityaids.co.uk

www.themobilitymarket.co.uk

www.preloved.co.uk

www.mobility-sale.co.uk

www.ebay.co.uk

www.fledglings.org.uk

www.theactfoundation.co.uk

www.actionforkids.org

www.childrentoday.org.uk

www.familyfund.org.uk

www.caudwellchildren.com

Spotlight on...



Rakemark Respite is a newly formed respite facility catering for all children with special needs and disabilities between the ages of 4 to 8 years of age. It was founded by a team of eight mums living in Uttoxeter, most of who have their own child with special needs or a relative with special needs.

Rakemark is Ofsted registered and opened Easter 2011. The respite facility will operate at Tree Tops in Uttoxeter on Mondays, Wednesdays and Fridays in every school holiday.

They would love to hear from any parent interested in using the special facility.

Please contact Zoe Hall, Manager, for more details on 07521 643 949 or visit

www.rakemarkrespite.co.uk

React - Rapid Effective Assistance for Children with Potentially Terminal illness is a dynamic charity working to improve the quality of life for financially disadvantaged children with life-limiting illnesses living in the UK.

Our work is unrivalled by any other organisation and our passion and belief that every child should have comfort, dignity, and the opportunity to participate in life as fully as possible is our driving force.

React works to give these children comfort, dignity and where possible, greater independence. This past year, we have supplied a wide range of equipment from specialist wheelchairs, beds, baths, and mobility aids, to essential everyday items like washing machines and tumble dryers.

We also offer family holidays in one of our eight holiday homes around the country. This is often the only chance at a holiday for many of the families and children we help.

Please get in touch if you think there's anything we can help you with at

React
St Luke's House
270 Sandycombe Road
Kew
Surrey
TW9 3NP

Telephone: 020 8940 2575

Fax: 020 8940 2050



Spotlight on...

SWAN UK (Syndromes Without A Name) is back!

Did you know that between 30-40% of children with special needs don't have a specific diagnosis?

You may remember SWAN (Syndromes Without A Name), the support group for families with children who don't have a diagnosis, which sadly had to close in 2009.

Now it's back! The Genetic Alliance UK has secured funding to re-establish SWAN UK. Offering information and support to families, the project offers a friendly listening ear and raises awareness of what life is like with an undiagnosed genetic condition.

If you or someone you know is raising a child with an undiagnosed condition please encourage them to get in touch to see how the project can support them.

They're also looking for people who are willing to share their stories on their blog/YouTube channel, so if you are a parent of an undiagnosed child (or your child now has a rare diagnosis), a professional working with affected families or you yourself are living with an undiagnosed condition please get in touch.

The old SWAN website (www.undiagnosed.org.uk) is not fully operational at the moment but they're working to get the forum up and running again very soon.

In the meantime you can get in touch and keep up with what they're doing by calling 0207 704 3141 ext 110 or email:

SWAN@geneticalliance.org.uk

Twitter: @SWAN_UK or Facebook: SWAN UK (Syndromes Without A Name)



Meet our 2012 London Marathon runners!

Pete Williams, who works at Birmingham Women's Hospital and Christina Turrell, a School Nurse at Calthorpe Special School are running in the 2012 London Marathon for Contact a Family!

If you would like to sponsor them or support them in any way, please contact the West Midlands office on 0121 415 4624.



Spotlight on...

New projects from Contact a Family!

Families and Relationships

Family Life is a new two year project working with Children Centres and parent groups in England to raise awareness of the relationship issues that many families face when caring for a disabled child. There will be a dedicated relationships enquiry service and new resources for families. For more details get in touch with our Relationships information officer yvonne.mcgahren@cafamily.org.uk

Special Educational Needs and Disability

We also have funding for a two-year project to reach all Special Educational Needs Coordinators (SENCOs) and Parent Partnerships in England. Working with parent support groups, we will be offering access to information, ideas and advice on how best to support families with children with SEN and disabilities in schools. For more details about the project contact our information officer karin.beeler@cafamily.org.uk

.....and a reminder of what we offer here in the West Midlands

- Disability awareness training
- Workshops on financial support for families with disabled children
- See the West Midlands pages of the website for up to date information on region wide events, training etc. Please contact us if you have anything you would like advertised
- Events and workshops for families with disabled children
- Help and advice to new and existing support groups
- We're keen to give talks about Contact a Family to professionals and parents
- We're always looking for opportunities to have stands at events, conferences etc

The Editor retains the right to omit, include or edit any contributions. The views and suggestions in this newsletter are those of individual contributions and not necessarily supported by Contact a Family. Contact a Family cannot accept responsibility for any goods or services mentioned in or enclosed in this newsletter.

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0808 808 3555



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