

contact a family
for families with disabled children

incorporating
The Lady Hoare Trust

in **contact**



The newsletter of Contact a Family North East

www.cafamily.org.uk/northeast

Issue 41

Summer 2010



Useful Vision Drama

Pictured left are children and young people with a visual impairment who took part in recent drama workshops. See page 6 for details of more workshops taking place in the North East.

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Contact a Family would like to thank Northern Rock Foundation for their continued support of the North East Office



**northern rock
foundation**

Contact a Family News

Welcome Jo - New Local Volunteer Parent Representative

Hi everyone, my name is Joan Barron; I'm 46 years old and live in Middlesbrough with my daughter Vicky who is 18 and has Dyspraxia and moderate learning difficulties.

I have just joined the Contact a Family organisation as a Local Volunteer Parent Representative which I am very pleased about and I will be putting my services out in the Middlesbrough and Redcar & Cleveland areas. The reason for doing this is because I believe every child, teenager and adult and their families deserve the best help and support that is out there.

When Vicky was diagnosed with Dyspraxia, I did not have a clue what it was as I had never heard of it. However, Vicky deals with this by accepting it and knows that she is a very special young lady. She is a very outgoing girl which does leave her very vulnerable in many ways as she trusts everybody. Vicky attends college and is doing a course on health and care alongside skills for working life. This has been very difficult, however with the help and support of myself and the tutors, Vicky has just about completed the course this term.

Vicky is academically aged 7-9, but we are hitting the usual teenage changes and challenging times, which I just deal with as each day comes along. We laugh together, we cry together, but we usually get to where we want to be in the end.

I myself have done other voluntary jobs in the past with the Citizens Advice Bureau and Justice Support work, which I did enjoy at the time. I am now just looking forward to getting out there and giving whatever support I can to those who need it.

Jo has only just started in this new role so look out for her full contact details in the next edition of In Contact.

Jo joins Bob Mitchell who is our Local Volunteer Representative for the South Northumberland area. Bob's contact details are on page 8 of this newsletter so please get in touch with him for local queries or if you would like more information about Contact a Family.

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Publications Update

Contact a Family Publications

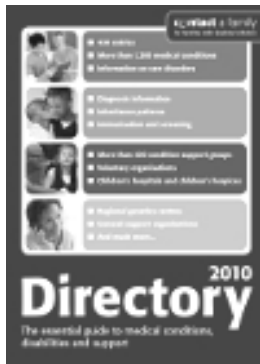
A new version of our **Holidays, Play & Leisure** fact sheet has recently been produced. This guide provides some information about the play and leisure options that may be available and suggests ways access for disabled children could be improved.



We also have a new version of our very popular **Checklist for Parents** which gives families details of some of the common benefits and financial support available and information on who can claim these.

If you would like a free copy of either of these fact sheets, please just give us a call on **0191 213 6300** or send us an email at northeast.office@cafamily.org.uk

You can also download copies from our website at www.cafamily.org.uk



The **2010** edition of the **Contact a Family Directory** is now available. If you work with children or adults affected by disability or additional needs, our Directory is the vital resource for you. The directory has details of 400 UK Support Groups for parents, families and carers and information on more than 1,200 conditions is included.

The Directory is available in paperback for £40 or as an annual subscription to the online version for £17.25. Order the Directory and you will also receive a free copy of our popular wall chart detailing benefits, practical help and support available for families with disabled children.

For full details or to get hold of your copy of the Directory, please see our website at www.cafamily.org.uk/medicalinformation/subscribe.html or call our Head Office on **020 7608 8700**

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CBIT - Local Information

The Child Brain Injury Trust (CBIT) has been working with families for over twenty years. They have developed a service for families to use in whichever way they feel most comfortable; some families dip in and dip out as their needs change, others are involved with CBIT for years.

Acquired Brain Injuries (ABI) include those resulting from illnesses such as Meningitis or Encephalitis, from accidents, stroke, poisoning or brain tumour. When a child acquires a brain injury, there is a ripple effect which impacts on many people.

The child them self has rehab ahead of them, with all the frustration that brings. They may return to their old school or attend a new one; they may struggle with things they could do before, and all the anxieties of teenage-hood are magnified for a young person with ABI.

Parents may be faced with a child very different from who they were, with a completely new set of worries, responsibilities, hopes and day to day routines; their lives can revolve around appointments, therapists and assessments, whilst still trying to keep things normal at home. Siblings are faced with a brother or sister who may look and behave differently from before. They may feel guilty, left out, and have a need for attention. Or they may feel that they should compensate and just cope. The list goes on; grandparents, aunts, uncles, cousins, neighbours, teachers and friends are all affected by the injury.

CBIT can provide emotional support, advocacy at meetings and a friendly face at the hospital who doesn't use medical jargon. Their officers can signpost to the right services for your child, can help with financial support, applications, assessments and information. They have experience in a range of issues and can provide training to schools. They organise social events so that families have the chance to meet each other and have fun at the same time.

CBIT are delighted to be in the North East and encourage families who believe they may be able to gain support from them to get in touch. You can email Miranda Barty-Taylor, Child and Family Support Officer for the North East at mirandabartytaylor@cbituk.org and, from the 1st July, you can give her a call on **0191 2308095**. More information about CBIT can also be found on their website at www.cbituk.org



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Research Request

Is drooling saliva a problem for your child? Has it been a problem in the past?
Has your child had treatment for drooling?

In the UK, several different treatments are given to children to treat drooling. Most children with this problem are given patches to wear on their skin. The other children are given a medicine by mouth, or by nasogastric/gastrostomy tube. There have not been research studies comparing whether patches or medicine work best to reduce drooling. Also, the side effects of these two treatments have not been compared. Therefore we don't know which treatment families prefer.

What is this research study?

Paediatricians and therapists in Newcastle want to find out whether patches or medicine are more effective at reducing drooling, and which of these treatments has the least side effects. They are applying for funding for the necessary research study.

They need your help to design the research study

Involving families in designing any study of their children is very important. They need to know what problems drooling creates for children and their families. They also need to know whether families would be likely to take part in a study and ideas on the best ways to help families stay in the study.

You can help by completing an anonymous survey

If your child has a drooling problem, or used to have a problem, please complete the online anonymous survey. The survey takes only three minutes to complete. At the end of the survey, there is information about a parent meeting to discuss your ideas about the study design. Attending this meeting is voluntary – they hope some parents will be interested.

Please follow this link to complete the survey:

<https://www.surveymonkey.com/s/parentsdroolingsurvey> or if you would prefer to be sent a paper version, telephone **0191 282 4701** or email:

Charlotte.Buswell@nuth.nhs.uk

Thank you.

Dr Jeremy Parr and Charlotte Buswell, Newcastle University and Newcastle Upon Tyne Hospitals NHS Foundation Trust

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Local News

Useful Vision UCAN Drama Workshops

As featured on the front cover, Useful Vision are holding free Drama Workshops at Dance City, Newcastle on **27th, 28th & 29th July 2010**. UCAN is about pure encouragement and fun, and this workshop is open to vision impaired children aged 8 years and over of all abilities. The aim is to boost young people's confidence and self esteem.

Children and young people can learn new skills and improve physical and vocal confidence whilst having fun and making new friends. Vision impaired young people will experience participating in the arts, acting in a friendly and safe environment and ultimately being part of a production. Young people do not need any drama experience to join the course.

The workshop runs from 11am - 3pm each day for 3 days with a performance on the last day, Thursday at 2pm, to which everyone in the family is invited to come and watch. Children will need to bring their own pack lunches & snacks and wear appropriate clothing. Parents/carers can leave their child at the workshop for part/all of the day but this must be by pre-arrangement with the Useful Vision office. If you would like further information or if your child would like to attend this fun, imaginative workshop please contact Useful Vision on **0845 60 48 491** or email georgie@usefulvision.org.uk

Gateshead Inclusive Summer Fun Day

Gateshead are holding a fantastic free summer fun day for all the family on **Thursday 29th July 2010** from 11.30am to 3.30pm at Gateshead International Stadium. There will be a whole range of activities on offer, just some of these are detailed below:

Animals from Bill Quay Farm

Bike Rides with the Gateway Wheelers

Fairground Rides & Bouncy Castle

Activities & Games

Gymnastic Display

African Drums Display

Balloon Man

Sports

Sandpit & Play Area

Graffiti Art

For further details of all the activities on offer call Gillian Newman but no pre-booking is required to attend the day. Gillian can be reached on **0191 433 5144** or e-mail GillianNewman@Gateshead.Gov.UK

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Local News

Disability North Children's Equipment Open Day

A Children's Equipment Demonstration event is taking place at the Dene Centre in Newcastle on **Thursday 8th July 2010**

The drop-in session will run from **1pm to 6pm** and will have equipment on show from Altonaids and R82. The equipment will include walkers, wheelchairs, seating, buggies and standing frames. Families will also have the opportunity to speak to therapists and information officers from Disability North, as well as representatives from Contact a Family, North East Special Needs Network and Whizz Kidz.

For more information please contact Carolyn Forster on **0191 2336715** or email **ilrc.enquiries@disabilitynorth.org.uk**



SNAPS - Special Needs Activities with Parents Support

SNAPS is a parent led support group in the Tees Valley which provides term and holiday activities for the whole family who has a child or young person with special or additional needs, age range 0-25 years. The group started in 1999 and has been growing ever since. Activities include Swimming & Sporting activities, Soft Play, Dance, Arts & Crafts, Games Sessions, Theatre Trips and more. There is usually no need to book – so families can come along and try out activities.

Families are given a chance to enjoy activities together and also get an opportunity to meet with others in similar situations. Please note that Parents/Carers/Guardians are responsible for their own children/young people.

SNAPS Plus for 18 -25 year olds with Carers attending is held on the first Wednesday of each month in the function room at the Mile House Pub from 7.00-9.00pm.

The group also runs **S.N.I.P.S**—Special Needs Information & Parents Support which meets every Wednesday during term time from 10am-12noon and is a chance for parents/carers to have a coffee, a chat and a chill.

For full details of all meeting and activity dates, please contact Ruth Benson on **01642 530292** or email **r.benson4@ntlworld.com**

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Wills & Trusts Seminar

Wills and Trusts Seminar

In conjunction with Irwin Mitchell Solicitors, Contact a Family is running a Wills & Trusts seminar for parents/carers with disabled children aged 0 to 19 on **Friday 9th July 2010** from 10.00am - 12.00pm at the Dene Centre, Newcastle.

The aim of the seminar is to give parents/carers useful information and the opportunity to ask questions about concerns you have. The seminar will be facilitated by Irwin Mitchell and will be followed by a free buffet lunch.

Places are limited so if you would like to attend, please call us on **0191 213 6300** or e-mail **northeast.office@cafamily.org.uk**

Contact a Family North East & Cumbria Local Contacts

Family Support Worker for Cumbria

Debbie Armstrong is our Family Support Worker in Cumbria. Debbie can provide one to one support & help with lots of information about local services etc. You can contact her on **01228 550069** or by email at **debbie.armstrong@cafamily.org.uk**

Volunteer Parent Representative

Bob Mitchell is in Northumberland and is happy to help local parents & professionals who would like more information about Contact a Family. You can contact him on **07532450218** or by email at **bob.mitchell@cafamily.org.uk**
(Jo Barron's details will feature in the next edition of In Contact)

National Freephone Number - 0808 808 3555

Contact a Family's **National Freephone Helpline** for parents of disabled children is open from Monday to Friday 10.00 a.m. to 4.00 p.m. (& 5.30 - 7.30 p.m. Monday)
The text phone number is **0808 808 3556** and Language Line is available for parents whose first language is not English

If you did not receive this newsletter at your own address and would like to be added to our mailing list please give us a call or write to us at Contact a Family, The Dene Centre, Castle Farm Road, Gosforth, Newcastle upon Tyne NE3 1PH.

Tel/Fax - 0191 213 6300

E-mail - northeast.office@cafamily.org.uk Website - www.cafamily.org.uk/northeast

The next edition of **In Contact** will be circulated **Autumn 2010**

The views and suggestions in **In Contact** are those of individual contributors and are not necessarily supported by Contact a Family.

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