



All the Fun of the Films

A large number of families enjoyed free screenings over half term in both Newcastle and Durham.

Pictured here are the Crich family who came along to Durham and thanks to the generosity of Paul George and his colleagues from Siemens enjoyed not only the screening, but also a free raffle, goody bags and drinks & sweets too.

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Contact a Family would like to thank Northern Rock Foundation, Big Lottery Fund and the Freemasons Grand Charity for their continued support of the North East Office

Contact a Family News

Mishy Holt

Very sadly Mishy's son Josh (aged 20) died last month. Mishy has been a Voluntary Parent Representative for Contact a Family since before Josh started school and has been the Family Worker for Teesside for the last three years so many of you will have met Mishy and if you live in Stockton/Yarm, Josh too.

Josh had Pallister Killian Syndrome, a very rare condition. Over the last year, Josh had been at residential college, something he was enjoying very much. If you ever met Josh, you would know of his keenness to collect good quality stationary and to show it to you - not to touch but to admire! His sense of humour was legendary, though probably not appreciated so much if you were the one locked in the cellar of his father's pub! Josh's big smile often gave his pranks away and his smile will be sadly missed by all who knew him.

Mishy sends thanks to all of you who have sent cards and kind words to her during this time.

Please note, for the moment the Family Worker service is suspended. If you have any queries, please contact the North East office on **0191 213 6300** or by e-mail at **northeast.office@cafamily.org.uk**

New Publication

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, please call the Contact a Family North East office on **0191 213 6300** or you can download it from our website at **<http://www.cafamily.org.uk/bullying.pdf>**

Contact a Family North East 0191 213 6300

Local Parent Involvement

Local Parent Involvement

Contact a Family is part of the Together for Disabled Children partnership that has been selected by the Department for Children Families and Schools to support Aiming High for Disabled Children. Many of you will know that Contact a Family has been at the forefront of work to improve participation of parents of disabled children for many years and over 2008, parents from across the North East have worked hard with us and local professionals to ensure that the views of parents and carers influence local strategic planning for disabled children.

Many Councils and Primary Care Trusts across the North East have encouraged and supported parental involvement. Local champions who work at senior management levels have ensured that parents are able to take part in local events by funding large conferences in very pleasant venues. As a result, we are starting to hear from parents that they are seeing significant changes driven by their views. A culture of healthy collaboration is now growing between parents and professionals working together to change the way services are delivered.

CONGRATULATIONS to all the parents, grandparents, carers and professionals who have given their time to be involved so far – you are all amazing! Since our last Newsletter highlighting events in Newcastle, Durham, Sunderland, Northumberland and North Tyneside at the beginning of the Autumn, we have now seen further Parent Conferences capturing local parent contributions:

Parents 4 Change - Middlesbrough at Middlesbrough Football Club. An event organised to bring parents and carers of children with additional needs together to look at how parents can positively influence developments in disabled children's services. Next event will be on Wednesday 11th March 2009.

Small Steps=BIG CHANGES – Redcar & Cleveland at Gisborough Hall. The first Parent Carer Conference was designed by parents for parents to bring local families together to hear about and contribute to service change. Next event at Gisborough Hall on Wednesday 13th May 2009

Listen for a Change – South Tyneside at Little Haven Hotel. This first Conference designed by a united group of parents who want to see positive changes happening in disabled children's services. Next event in April 2009 at Little Haven.

United 4 Change – Stockton on Tees at Parkmore Hotel. Again parents and carers coming together to contribute to this exciting agenda. Next Conference date to be decided.

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Daslne Update



Daslne Update

Daslne, the Database of Children with Autistic Spectrum Disorder Living in the North East was five years old in October 2008.

Over 700 children in Northumberland and Tyne & Wear are now registered on the database. Parents have provided information about their child's schooling, abilities and problem behaviours. With this snapshot information, the Daslne team can provide summaries which help local authorities and voluntary organisations in planning services. Furthermore, families can be informed about autism research projects which are underway - in the past year 4 projects have received help with recruitment from Daslne.

Plans for the future include a conference in March 2009 for parents and professionals entitled "Searching for Answers" highlighting the essential contribution from families make to research in the puzzling field of autism.

Local authorities and health trusts have to make difficult decisions about how best to use their funding. We have asked for an annual contribution from each of the 6 local authorities of £4000 for maintenance of Daslne but this contribution is under threat. Accurate data are vital in planning services and before Daslne started, local professionals did not know how many children with autism spectrum disorder lived in the area. Daslne would be very grateful if families could write to the Director of Children's Services in their local authority to ask for continuing support of the Daslne database.

For further information about Daslne, please contact:

Mary Johnson

Daslne, Institute of Health and Society, University of Newcastle,
Sir James Spence Institute, Royal Victoria Infirmary, Newcastle Upon Tyne
NE1 4LP.

Telephone **0191 282 1400**, e-mail **daslne@ncl.ac.uk** or check their website at
www.ncl.ac.uk/daslne

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Conductive Education

Step Together Centre

(Division of The Child Care Action Trust Registered Charity No. 1076757)

The Child Care Action trust provides Conductive Education throughout the North East for children with cerebral palsy & other motor disorders in its Step Together Centres. Recently they have moved premises to Newton Aycliffe and opened two satellite centres in South Shields & Marton. Conductive Education is based on the Hungarian "Peto" method. It is a special education & rehabilitation for children and adults with motor disorders. They are offering group and individual sessions where children can learn how to reach their full potential and how to improve their mobility in a playful way.

They are providing Conductive sessions from as early age as 6-8 month up to adulthood and as well for adults with Cerebral Palsy, Parkinson's disease, Multiple Sclerosis and after effects of strokes. For further information, see their website at www.steptogether.org.uk or contact Viktoria Kincses (Centre Manager) on **08452305980/ 07828042673**



Heel and Toe

Heel and Toe is a new regional charity based at a centre at The Meadows in Spennymoor providing conductive education to teach children with Cerebral Palsy and other 'Motor' Disorders how to cope with everyday life, through meaningful one-on-one and/or group sessions.

Conductive Education is a system of rehabilitation; to achieve this, the brain utilises its re-organisational ability. This is appropriate for conditions where diseases or damage to the central nervous system affects the person's ability to control movement.

It is a fundamental principle of the charity that no child is denied Conductive Education due to lack of money. The centre provides sessions for children from 12 months old to 16 years old. Sessions include group sessions, one-on-one sessions, school time sessions, after school sessions, holiday camps and Saturday morning sessions.

For further information, please contact the Heel and Toe team on **0844 3350512** or email info@heelandtoe.org.uk or visit the website www.heelandtoe.org.uk

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Local News

Engage TV

ENGAGE TV are a Newcastle-based production company specialising in programming made by and for people affected by disability. They are working on a documentary which aims to give a broad view of some of the issues parents encounter when their child is disabled and are looking for a participant who may be interested in sharing their experiences. They are looking for a family who has a child between the ages of 2 and 12 who is affected by a disability and who wishes to share their story, specifically in the areas of social and medical analysis of their child's condition.

Partnering organisations from the medical community are already on board and the filmmaker has a 6 year history in supported living with people affected by conditions as broad as Autism, Epilepsy and visual impairment. They are supported by award-winning filmmakers at Superkrush Films who work heavily in the community providing learning and training around media as well as produced feature films, dramas, corporate films and TV commercials.

If anyone is interested then please contact Charly Conquest for more information on **0191 260 2381** or **07908405014** or by e-mail at **charly@engagetv.co.uk**
All enquiries will be dealt with under strict confidentiality

Green Box - for packing and mailing support

Whether it's your newsletters, marketing flyers, magazines or conference packs, Green Box can solve all your distribution problems.

Green Box is a Hextol Foundation company, giving employment opportunities to people with disabilities who otherwise find it very difficult to find work. They offer the support of an enthusiastic collation and packing team; backed by a thorough quality control process. And, besides packing and posting, they can offer graphic design, short-run print and database maintenance services too.

Your business allows their staff to gain real job satisfaction, working in a positive and supportive team, developing capability, growing confidence and offering a better future. It can make all the difference.

For more information, contact Cherie or Chris on **01434 605253**: or email them at **greenbox@hextol.org**: or see the Hextol Foundation website at **www.hextol.org**

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Local News

Useful Vision Events

Useful Vision (UV) is a registered charity established in the North East to help blind and visually impaired children get the most out of life. They offer a number of services including family days out and activities. Forthcoming events include:

- A Family Fun Day at The Alan Shearer Centre on Sunday 1st February 2009
- A Cookery Course (4 x 2 hour lessons) in March 2009

Families need to register with UV to take part, but registration is free and will enable families to be contacted with details of other events and trips that they are organising.

Please do email them if you are interested in any of the above events - more information will be available soon. They would also be delighted to hear from you if you have any events/ trips/courses that you would like them to organise. Please email them at info@usefulvision.org.uk or give them a call on **01434 682160**

Power Chair Challenge Club North East

Is your child a power-chair user who wants to get out and have some fun? Then why not join this new club whose motto is "Breaking the Chain, Having Fun"

Power chair user Mary Laver is setting the group up to promote fun and challenges for power chair users regardless of age and ability. It's aim is to enable people living in the North East to get out and enjoy using their chairs.



For more information contact Mary on **0191 266 5197** or **07975 649162** or by email at mary.laver.e2e@googlemail.com

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Children without a Voice

Children without a Voice

Readers may remember that in the Spring 2008 edition of "In Contact" we included a request from local parent Dawn Davies for any families who wanted their children to feature in an photographic exhibition she was putting together to raise awareness of the needs of children with communication needs.

Dawn embarked on meeting 27 families of children with profound communication and speech difficulties. Her mission was to see if they knew anything about AAC (Augmentative and Alternative Communication) or had access to Communication Aids. She was not phased by the fact that the majority of families knew nothing about AAC and communication aids. No-one had informed them of these devices and most were in the dark as to how a communication aid could benefit their own children. Dawn said: "If I have managed to spread the word of AAC to these families then hopefully they in turn, can tell more of their friends and keep sharing the knowledge.

The photographic exhibition was held in August 2008 in Ferryhill and will be shown in a bigger form next April at the Discover Centre in Bishop Auckland. Anyone who would like to get in touch to know more about AAC can contact Dawn by email at dawnedavies14@hotmail.com or tel no **07921 544486**.

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 textphone 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

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