

**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](http://www.cafamily.org.uk/northeast)

Issue 36 Spring 2009



### **Brave Heart of the North East**

Pictured left is Lyndon Longhorne receiving his award from Carol Malia at the Brave Heart Ceremony held at St James' Park in December last year.

See page 4 for his mam's story on how reading about the awards in this newsletter lead to Lyndon's success.

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# Contact a Family News

## Mishy Holt

Mishy has recently resigned her post as Family Worker for Teesside. Many of you will have met Mishy over the last 18 years whether as a Volunteer Parent Representative for Contact a Family, or more recently as a member of staff.

Mishy was the first representative of Contact a Family in the North East paving the way for a local office by building knowledge of our organisation and its services as a volunteer. She campaigned to improve services for disabled children by helping to set up local parent support groups who provided information and valuable mutual support to each other.

Mishy has met and supported many families who have children with special needs or disabilities in Durham and Teesside and worked with professionals to help formulate changes in service design with her extensive experience as a parent. We will miss her enormously and know from everyone we have met recently that she will be missed by families and workers on Teesside too

**Thank you Mishy, you are a star!**

## Cumbria

We have been awarded a three year grant from the Northern Rock Foundation to continue our work in the North East and to expand our services into Cumbria which recognises that north east Contact a Family is often approached by families from Cumbria who use some local services here in the North East.

## Listen Up - Have you heard any of our Podcasts?

Did you know there are now a range of Podcasts available on the Contact a Family website? Podcasts are audio files that can be listened to or downloaded from our website so it could be a good way of finding out about loads of information as an alternative to reading leaflets, factsheets etc. Topics covered include Special Educational Needs, Benefits and "My Son Has Autism"

We are looking for families to take part in our podcast series on what it is like for families affected by rare disorders. For more information contact Sasha Henriques, Information Officer (Rare Disorders) on 020 7608 8714 or e-mail: [sasha.henriques@cafamily.org.uk](mailto:sasha.henriques@cafamily.org.uk)

To listen to any of the podcasts, visit the website at

<http://www.cafamily.org.uk/news/podcasts.html>

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# New Vol Parent Rep

## Granda Bob - New (Old!) Volunteer Rep for Northumberland

My name is Bob Mitchell. My wife Monica and I care for three of our grandchildren; Dylan aged 13 and Anissa & Katrina aged 11 yrs, who live with us. We help where we can with Kai our youngest grandson aged 5, who lives with his mam, our daughter Sarah. We also provide support for Monica's mam, Monica Snr, who lives nearby.

As anyone familiar with care and support will understand, we don't make any ambitious plans, and often cannot be contacted directly. I do apologise to anyone who may have to wait for a reply to a phone message or e-mail, your patience is appreciated.

I have lived in a mining community all my life and worked at a number of local collieries for almost twenty years, then moving into electronics, education and the audio-visual industry. I left work in order to focus upon caring for the children which was obviously going to require the attention of both Monica and myself.

All our grandchildren are diagnosed with Coffin-Lowry Syndrome ([www.clsf.info](http://www.clsf.info)) and each has differing features relating to this rare condition. All are in Special Education and at different schools reflecting their capabilities. Dylan and Katrina have severe learning difficulties (SLD) whilst Anissa is in a moderate learning difficulty (MLD) school. Kai's abilities have yet to be fully assessed; he is very slightly built, wearing 2 yr clothes, has a heart problem awaiting surgery and is profoundly deaf. Dylan also has a heart problem, unfortunately this cannot be addressed with surgery, with delayed physical and mental development and very little speech. Katrina experiences "Drop Attacks", where an unexpected noise or touch results in an abrupt and dramatic collapse. She also has delayed physical and mental development with a bowel disorder. Anissa has very little in the way of physical difficulties, but has some mental development delay and can be extremely delicate psychologically.

I would like to thank everyone in both the local & national offices for the welcome I have received since agreeing to assist Contact a Family and for the resources made available to help others. I have no specific childcare qualifications, but a considerable number of years experience of vastly differing circumstances which, with the resources mentioned, I hope to be able to help parents and promote Contact a Family in some of the more isolated areas of our county. I can be contacted by telephone on **07532 450 218** or by email at [bob.mitchell@cafamily.org.uk](mailto:bob.mitchell@cafamily.org.uk)

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# Brave Heart Award

## Tammy's Story

In the Autumn 2008 edition of "In Contact" you may remember we featured an article about the Brave Hearts Awards being held in the North East. Here is Tammy Shevel's story about her own Brave Heart.

"On the 4th December 2008, my son Lyndon Longhorne attended the Brave Hearts of the North East awards at St James' Park. I nominated Lyndon for the award as he is so inspiring; he complains about nothing and although he has a severe disability, it doesn't stop him from doing anything. Lyndon had meningococcal septicaemia in August 1996 aged 9 months. He is now 13 and a fantastic teenager.

When I received a phone call to say Lyndon had won the award, I was overwhelmed. I told him we were going to St James' Park and he couldn't sleep that night he was so excited. Lyndon met Newcastle United footballer Mark Viduka, which he didn't expect and got to go on a tour of the ground.

The gift he received was a Playstation 3 with games. I kept that as a surprise from Lyndon. He was the only child who hadn't said what gift he would like; I knew he was desperate for the Playstation! Lyndon also received the Brave Hearts Badge with his award.



The day was fantastic; it was lovely to be made to feel special and every single child there really did. It was a day Lyndon will treasure, as he has had his fair share of problems so he did deserve to be awarded the Brave Heart award. Not to forget Carol Malia presenting the award to Lyndon, who kissed her on the cheek and gave her a pat on the back. Carol was lovely and Lyndon enjoyed meeting her

If it wasn't for the Contact a Family newsletter, we wouldn't have known about the Brave Heart awards so a big thank you to you all"

Congratulations to Lyndon and all the other Brave Heart award winners - we hope you all had an equally fantastic day.

Our thanks to The Northern Echo for their permission to include these photographs.

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# Getting Involved - News

## National Indicator for Disabled Children

Some of you may have received a questionnaire from the Government asking you some questions about services for your child – not just your disabled child!

### What is a National Indicator?

A National Indicator will measure how good services are for children – specifically in the case of Indicator 54 for disabled children and their siblings.

### Why is it important to fill this Questionnaire in?

No Indicator has focussed on disabled children before and by filling the Indicator Questionnaire in, you will be able to give the Government a clear indication of what is working well for your child and what isn't. Clear information from service users (you) will help local areas channel money and resources where they are needed.

### Why bother – will anything happen?

One example shows that the introduction of a National Indicator looking at referrals to specialist health services from GP surgeries significantly reduced waiting lists.

### Tell me more

A sample of parents will be receiving a questionnaire in the Spring/Summer of 2009 - it will ask you about your experiences of services you receive from Health, Social Care and Education. The questionnaire will be sent out through the British Market Research Bureau (BMRB).

The Survey is a unique chance to have your say – if you get the opportunity to take part, please do and encourage other parents to do the same!

## Local Parent Participation

We are hearing about lots of exciting changes driven by parents' points of views across the North East. Parents are coming together to hold Conferences, Focus Groups and Information Days and Parties!

Sociable events that are leading to new ways to provide information make services easier to manage and provide clarity about how to access what is available. If you are not involved locally yet and don't know what is happening in your area, please call us to find out - there will be something near you.

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# Free Film & Conference

## Easter Fun - Free Cinema Screening

Duncan Scott, the manager at the Empire Cinema at the Gate in Newcastle has once again kindly organised a free Easter cinema screening for families to be held on **Sunday 19th April 2009 at 10.00 a.m.**

As with some of the previous screenings, this one will involve a fire evacuation but this will be kept to a minimum and will happen before the film starts. The fire alarm will only be on for 30 seconds to minimise disruption for children and wheelchair users will not be required to evacuate.

Places will be available on a first come, first served basis and the booking line will open on **Monday 30th March 2009 at 10.00 a.m.** We will know the film that is being shown at the time of booking so can give you the details then (it will be a new family film). The booking line number is **0191 213 6300**

Remember, you can bring siblings, grandparents and friends along too so come and enjoy some free film fun to finish off your Easter Holidays before the kids go back to school. We look forward to seeing you there.

## Regional Parent Partnership Annual Parents' Conference

Organised by the North East Parent Partnership Service, this year's conference is being held on **Thursday 18th June** at The Oakwood Centre, Eaglescliffe, Stockton-on-Tees. The day will begin at 9.15am for arrival and tea/coffee and the conference will run from 9.45 a.m. - 2.45 p.m. The conference will include a range of workshop options for parents which will include:

Person centred planning	Benefits
Living with Challenging Behaviour	Will Writing
Exclusions	Bullying
Transitions to adult health services	Sexual Health

The conference is free for parents and includes lunch and refreshments. **Free transport will also be available for parents between Darlington train station and the venue.** For more information and a booking form, please contact Kerry Ford on **01325 254484** or by e-mail at **kerry.ford@darlington.gov.uk**

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# Local News

## Dyslexia North East

Dyslexia North East is a voluntary group of people who care passionately about improving educational opportunities for children and adults with specific learning difficulties or Dyslexia. This can include those with Dyspraxia, Autism and ADHD, which can often co-exist.

The group includes parents, carers, teachers and many others from all walks of life. They welcome anyone who is interested in finding out more, and who might like to help them, or just come along to meetings and events. They have monthly meetings in term-time held at Royal Grammar Junior School in Jesmond, Newcastle with speakers on relevant topics, and arrange other events and workshops at different venues. Information leaflets and support with advice is available, together with the loan of books and other resources to help children at home.

On Saturday 4th April from 10.00 a.m. – 12 noon, they are having a “Barebones Story Walk” given by Deb Court for children with Dyslexia, Dyspraxia etc who are aged 7-12 years old. This will be FUN and adults who accompany children will be offered information about the ACE Dictionary by Lindsay, a Literacy Support Teacher. Other resources to help children at home will also be available.

They also have a DYSLEXIA FUN DAY planned for Saturday 20th June at Stannington Village Hall from 2.00 - 4.00 p.m. So please put this date in your calendar.

If you would like further information, please contact Liz Ferguson at Dyslexia North East, 6, Green Close, Stannington NE61 6PE, telephone **0786 826 3696**, e-mail **info@dyslexianortheast.org** or see the website at **www.dyslexianortheast.org** Membership is £10 per family per year with free attendance at meetings, email network, Newsletter and support, or £2.00 to attend a meeting for non members.

**E-mail bulletins reminder** .... If you have an e-mail address, don't forget to sign up for the Contact a Family North East bulletins. We include lots of information in these, including details of local events and activities that we hear about in between newsletters. To sign up, just send your details to our office at **northeast.office@cafamilly.org.uk** We have had a number of e-mails bounce back to us recently, so if you have changed your address, please let us know.

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# New Support Group

## Sunderland ADHD Support Group

Sunderland ADHD Support Group was set up by Linda New in September 2008. The group is for parents/carers of children/young people diagnosed with ADHD (Attention Deficit Hyperactivity Disorder) and is/are residents of Sunderland.

The group aims to support parents/carers via informal fortnightly meetings, information sharing, signposting to outside organisations if needed and monthly guest speakers. They are also aiming to deliver ADHD Awareness training to other organisations so enabling them to actively raise funds for the group as well as raise awareness about ADHD within the public and professional sectors.

Meetings are held at Sunderland Carer's Centre. Tea, coffee and refreshments are available and there is disability access. For details of the next meetings, contact Linda on **0191 5550109** or **07857008451** or by e-mail at **[lindanew66@yahoo.co.uk](mailto:lindanew66@yahoo.co.uk)**

If you know of any parent support groups in the North East region who would like to be featured in a future edition of "In Contact" please send details to us at Contact a Family North East by email to **[northeast.office@cafamily.org.uk](mailto:northeast.office@cafamily.org.uk)** or give us a call on **0191 213 6300**

## 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

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](mailto:northeast.office@cafamily.org.uk) Website - [www.cafamily.org.uk/northeast](http://www.cafamily.org.uk/northeast)

The next edition of **In Contact** will be circulated **Summer 2009**

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

Contact a Family cannot accept responsibility for any goods or services mentioned in or enclosed in **In Contact**

# Spring Special



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Get out There - Local Leisure Opportunities  
Spring 2009

Hi Everyone. Firstly, apologies for the lack of a Leisure Insert in the last edition of our newsletter but we're back with a Spring Special for this, our 25<sup>th</sup> Insert. We hope you find something of interest for you and your family.

## **Action for Blind People - Newcastle Actionnaires**

The Lakeside Centre, Killingworth.

Actionnaires clubs provide opportunities for blind and partially sighted children of school age to participate in sports in a safe, structured and fun environment. For blind and partially sighted children aged between 8 and 16 who are keen to play sport, get fit, make friends and have fun.

Under 8's are welcome as long as they come along with an adult and the adult stays with them during the session. Clubs offer multi-sports sessions run by professional coaches. Children are also welcome to bring along a sighted sibling or friend if they wish.

The Newcastle Actionnaires was recently launched to join those already taking place in Sunderland and Middlesbrough.



For more information, contact Anthony Hall, Sports Development Officer (North East) on **07595 090 862** or see the website at <http://www.actionforblindpeople.org.uk/> and follow the links to Kids in Action

## **Teesside Down's Syndrome Support Group - Leisure Activities**

The group run a range of activities for families who have a child with Down's Syndrome. Future events include an Athletics Event at Clairville Stadium in Middlesbrough on Tuesday 9<sup>th</sup> June from 10.00 a.m. to 2.00 p.m. in conjunction with Middlesbrough Sports Development. For information and to book places at this event, please contact 0870 765 2121

## **Northeast Special Needs Network (NSNN) - Family Fun & Information Day**

NSNN are holding a fun and information day in conjunction with Newcastle Toy and Leisure Library on Saturday 25<sup>th</sup> April 2009 from 10.30am - 12.30pm. There will be a face painter, magician, soft play and arts & crafts and refreshments

There will also be several organisations which can offer support and services for families of children and young people with disabilities to come along to share information with you.

This event is free to families. For more information call NSNN on **0191 281 2485**

## Alan Shearer Centre

During the Spring season (between 23 February and 4 April) the Alan Shearer Centre in Newcastle is having a Fun Day Special every Saturday from 10.00am - 4.00pm

- £5.00 per group of five for use of the Centre excluding use of the hydrotherapy pool.
- £15.00 per group of five for use of the Centre including a 45 minute session in the hydrotherapy pool.
- £12.00 per group for an hour session in the hydrotherapy pool only.  
(All hydrotherapy pool sessions must be pre booked)

To book places or for more information, please contact them on **0191 267 8118** or email [AlanShearerCentre@stcuthbertscare.org.uk](mailto:AlanShearerCentre@stcuthbertscare.org.uk)

## Fishing With Tom

Fishing with Tom is a fishing/education charity which aims to introduce young people to fly fishing. The project has been running now for three years and has helped over 2589 children to enjoy the fun of angling in a safe and controlled way. There is a cost for each session, but these are kept to a minimum. All equipment is provided. They have limited disabled platforms (3) but will try to help everyone who would like to try fishing. There is a maximum of ten places at any one time, bigger groups will need to contact them to make arrangements.

To find out more about the sessions, please visit the website at [www.fishingwithtom.com](http://www.fishingwithtom.com) or call Tom Carroll on **07759 469032** or **01325 308049**

## Useful Vision Activities

Events in the North East for families who have a child with a visual impairment. Membership of Useful Vision is free.

Easter Farm Visit to Whitehouse Farm, Morpeth on Sunday 19<sup>th</sup> April from 11.00 a.m. to 3.00 p.m. Includes feeding the animals, indoor soft play area, decorate and take home shortbreads and the daily "beastie show".

Bring a picnic (indoor and outdoor picnic areas). Free entrance for Useful Vision families; friends and extended family £10.00 per head

Calvert Trust Children's Outdoor Activity Day on Saturday 27<sup>th</sup> June. Activities include Zip Wire, Sailing, Archery and Canoeing. Minimum age is 5 and activities are accessible to children of all abilities. Open to Useful Vision registered children and immediate siblings only; cost £7.00 per person. Bring a picnic (and blankets, folding chairs too). A named adult must accompany the children and be responsible for their care and supervision.

To register with Useful Vision or to find out more information, contact them on **01434 682160** or by email at [info@usefulvision.org.uk](mailto:info@usefulvision.org.uk)

## English Federation of Disability Sport

The EFDS website includes lots of information about clubs throughout the North East that offer sports and activities for people with disabilities. These include football, boccia, dance, athletics and swimming.

They also have details of specific events that are happening in the region that your children may like to attend.

To find out what's available see <http://tinyurl.com/dbrvo2>