

Link ~ Up

No. 94, December 2006

Having a ball

This job doesn't have many perks, but my invitation to the Market Harborough group's Ball repaid me for years of volunteering. Champagne and canapes, charming company, glamorous setting: I even danced for the first time since the 60s. Regretably, my style hasn't changed. The very best bit was the delightful spectacle of lots of people from outside the autistic community putting their hands in their pockets to support this fantastic group.

Do read Yasmin's beautiful speech given at the Ball - I wasn't the only one in tears - and Daniel's account of what it means to be an autistic child which was read at the Ball.

Lynda Lowe

We are all very sorry to say goodbye to Lynda Lowe of the County Autism Outreach Team. Lynda has given fantastic support to the families on her caseload and will be hugely missed. She has always given generously of her own time and the summer playscheme she has run for several years has been outstandingly successful. We shall make every effort to ensure it continues.

We wish Lynda all the best for her future career. Thanks, Lynda, you have made a real difference to many children's lives.

Any Volunteers?

I shall be standing down from the LAS committee in the summer of 2008, when I retire. At present I am acting as Chair, Secretary and Database manager, as well as producing Link-Up. I run the 100 Club and the Helpline and produce the Adult Directory. Help!

I would like to shed some of these responsibilities in order not to leave too big a gap when I stand down. Please give me a call if you are interested in volunteering to help the LAS. We need a gradual handover and I would be happy to work in tandem with anyone who could take over any of these tasks.

Kim Higgins

Welcome to Kim Higgins, recently appointed as regional officer at the NAS Nottingham office. Kim has been taking the time to attend our committee meetings and has been very helpful in keeping us up to date with NAS activities.

In response to the "Make School Make Sense" campaign, the NAS in Nottingham have put together Teachers' Packs. These are for parents of newly diagnosed children to take into school. We have a stock - call Lindy or Anne if you need one.

I hope you all have a wonderful Christmas and Happy New Year.

Lindy Hardcastle (Chair)

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Phoenix Theatre

Open Season

Tuesday 2nd January 2007

A special screening for children on the Autistic Spectrum, their families and friends.

Cost £2

Box office 0116 2554854



Useful Contacts



Leicestershire Autistic Society

Treasurer: Carole Heubeck, 5 Grey Crescent, Newtown Linford, Leics. LE6 0AA Tel: (01530) 244790

Chair/ Helpline: Lindy Hardcastle, 31 Flaxfield Close, Groby, Leics. Tel: (0116) 291 6958 e-mail lindy@flaxfield.demon.co.uk

LAS Education Support Worker: Anne Lewis Tel 07958 235015

Red Cross Advocacy and Family Support: Anne Lewis 0116 2710359 / 07921 492431

PDA Contact: Alison Mann 01509 561505

Jigsaw Contacts: Chair: Gillian Wisdish, 82 Lime Avenue, Groby, Leics. LE6 0EN Tel: (0116) 287 6747

Asperger Syndrome Support Group: Chair: Shelagh Wilson 0116 270 107 email:

shelagh.m.h.wilson@btopenworld.com
Website: aspergerleics.org.uk

Monday Club Project Manager: email themondayclub@hotmail.co.uk

Chair: Mrs. Jenny Fisher email – jenfisher@btinternet.com Tel. 0116 2595351

Oakhams/Melton SAC Club : contact: Mo Potter on (01664) 500688

Loughborough ASD Group : contact: Carole Heubeck, 5 Grey Crescent, Newtown Linford, Leics. LE6 0AA Tel: (01530) 244790

Rutland and Melton Support Group: contact Carole Gamble 01664 434502

Market Harborough Support Group: contact Yasmin Delargy home 0116 279 2419, mobile: 07763823282

Birchwood Support group: Contact Lesley Herbert 01664 565155

Castle Donnington Group: Contact Jane Sherwood 01332 850709.

Reality Support and activities for children and families, Contact Leisa Smith 078794 28553

Activity Club Contact: Jane Hall 07870 688973

Saturday Swimming Sessions at Bosworth Community College: Josh Wilson 07950 379447 email Josh@boscol.globalnet.co.uk

Children's Services

Leicestershire Educational Psychology Service: 0116-2845100.

Leicester City Educational Psychology Service: (0116) 221 1200

Leicestershire Autism Outreach Team: Contact George Thomas. (01530) 513600

Leicestershire Pre-school Support Worker: Jane Mansfield, (01530) 513600 Leicester City Learning and Autism Support Team: Tel: (0116) 225 4800

Rutland Autism Outreach: 01572 758496

Parent and Carers' Council:

Tel. 07786 626564 e-mail enquiries@parentcarercouncil.co.uk

Red Cross Family Support Centre: Anne Payne, Red Cross Family Support Centre, 54 Kenilworth Drive, Oadby. Tel: (0116) 271 0359

Services for Adults with Autism in Leicestershire:

Fosse Autism Service: Chris Howell, Leicester Frith Hospital, Groby Road, Leicester. Tel: (0116) 225 5335

NAS, Grovebrook House Resource Centre: Brook Street, Whetstone, Leics. LE8 6LA Tel: (0116) 286 6956

National Autistic Society (NAS): Helpline: 0845 070 4004 email autismhelpline@nas.org.uk

NAS Regional Office: Ester Vickers, Regional Coordinator, Central Region Kim Higgins, Regional Officer, Central Region

Castle Heights, 4th floor, 72 Maid Marian Way, Nottingham NG1 6BJ Tel: (0115) 911 3360

Befriending Scheme: Gillian Keeling email Gillian.Keeling@nas.org.uk Tel. 0116 236 7524.

Local Education Authority-run Schools with Autism Units:

West Gate School, Glenfield Road, Leicester Tel: 0116 285 6181

Maplewell Hall School, Maplewell Road, Woodhouse Eaves, Leics. Tel: 01509 890237

Newbold Verdon County Primary School, Dragon Lane, Newbold Verdon, Leics. Tel: 01455 82236

Birch Wood School (Melton Area Special School) Grange Drive, Melton, LE13 1HA Tel. 01664 483340

Netherhall School, Netherhall Road, Leicester LE 1 5TS Tel. 0116 2417258

Vale of Catmose College, Cold Overton Road, LE15 6ND Tel 01572 722286

SPECTRUM OF AUTISM

Recently we had a Ball to celebrate the Spectrum of Life and I delivered a speech to 190 people, many of whom had just a passing appreciation or knowledge about Autism. It brought back to the surface many emotions about how Autism has affected my family and I wanted to share some of them with you. You may well have heard this story before, but love it or hate it, it speaks to us all.

Imagine planning the trip of a lifetime to Venice. Imagine the plans you make....You read all the guide books, book a great hotel, plan an itinerary, even learn some Italian. You surf the net and plan your trip according to what you want to get out of it. You excitedly board the plane; have nibbles and G and T. The plane lands, you disembark and

Well, this doesn't look right. For a start it's bloody cold, flat, there are windmills, no car hire booking, you can't speak Dutch and there's no wine. Imagine the confusion, fear, anger, the isolation; as it would appear everyone else had the good sense to stay on the plane and proceed to Venice for an interesting and fascinatingly exciting trip. The trip you had planned and yearned for.

All the above emotions ebb and flow over time as you embark on a difficult but rewarding journey of raising a child with special needs.

We all have to learn to accept, live with and adapt to parenting a child on

the autistic spectrum and this is a deeply personal journey. No two journeys are the same with children with unique symptoms, difficulties and strengths.

People with autism find it hard to relate and communicate with others. They lack flexibility of thought and actions. They all share these difficulties but to different degrees. They all have their own unique personality, areas of interest, difficulties and talents. Autism is, as it were, a different colour in each person. Hence the Spectrum ranging from those severely affected, locked in a world of their own, to the genius savants of this world.

It is important to stress that along with difficulties there are many positive and wonderful facets to the spectrum. Some of the world's most innovative thinkers, explorers, composers and engineers, not to mention those pushing forward the boundaries of science and law, are on the spectrum.

We should try to celebrate and support those differences and be proud of such individuals. We all have something to learn from them.

Holland can be very beautiful. Consider the simple beauty and diversity of tulips, the intricate patterns of lace, the beer and the ingenuity of polders.

We are in Holland and are learning to live and accept life on the polders. That is not to say that I don't yearn for Venice from time to time with gut wrenching pain.

At the end of the day no matter how your child is affected they are just that. Your precious child you carried, nurtured; and you will move heaven and earth to help, support and guide them just like any other parent.

Personally I have the utmost respect for these individuals because they have to be extremely tough and courageous to survive. Imagine having to deal with the mysterious art of communication all day long. If we feel confused by landing in Holland just imagine how it must feel for them landing in Beirut without all our skills of communication, mediation and flexibility.

On our good days our children fascinate us from the simplest "mum" or eye contact to discourses on life the universe and everything.

"Its life, Jim, but not as we know it." That doesn't necessarily make it bad.

Special children, special families needing help, support, guidance and above all empathy. Hence the function of the support group. Every time we meet I am grateful for its existence and what it brings to so many. So many small ripples creating big waves.....

Go on supporting your group and help raise awareness so that the world can stop trying to jam our square children into round holes. Stand up for "squareness"!!!!!!!

Yasmin Delargy

NOVEMBER 2006 SPECTRUM M. H.

BALL

This was a great success and saw 190 people come together at the Shearsby Baths to celebrate the Spectrum of Life and raise funds for Autism. The ball committee did a great job and a lovely evening was had by all. A particular success were the two Information Boards compiled by Liz Karim on the Face of Autism, leaflets from the LAS and NAS and a board detailing our groups activities/projects. With the ticket sales, raffle and games we raised just over £2600. With the group's agreement and a special request from one of our members, donations will go to Jane Mansfield (Earlybird team) and Menphys SOS outreach. These funds will boost our fledgling multisensory toy library and help fund the swim sessions/play sessions.

SWIM SESSIONS

In view of the above we have decided as a group to fund bi-monthly swim sessions in the New Year. Due to the difficulties of securing a regular time we will have to book these as party slots and advertise per Email link via the LAS network. If anyone else is interested, please let us know your Email address or telephone number and we will forward dates/times. For family members only.

PLAY SESSIONS

These will also be bi-monthly and alternate with the swim sessions, so dates will be circulated in same way. These will take place on a Sunday afternoon and families will be invited for arts and crafts, sports taster sessions etc with drinks for children and accompanying adults. If anyone is interested, please let us know your Email address or telephone number.

MEETINGS

These have been well attended and although we will not meet in December, a new programme will be out for speakers in the New Year. The October session was held on the 1st Wednesday in November and was a card making session which was a great success and very therapeutic!!

SOCIAL SKILLS COURSE

As yet I have had no feed back from anyone who may be able to help us set up a week's course next summer for the older, higher functioning children but am eternally optimistic. Please pass onto all groups. If anyone interested in their child taking part or in helping/offering advice contact Yasmin.hdelargy@doctors.org.uk, or telephone Yasmin on 0116 2792419, mobile 07763 823282.

MAKE A STAND!!!!!!!!!!

Some people may believe that all autistic children are a pain

WE ARE NOT!!!!!!

We are merely children at play..... misunderstood children at play.

We may not see the world as others do, but that doesn't mean that we don't like it. Most of us enjoy the world we see.

We are like you, yet at the same time we are not.

Most of the time, we go at our own pace.

People often think we are terrors, but we're cool with that. This is because:

- 1) The person hasn't been with an autistic child for long.
- 2) The person hasn't asked them how the child feels.
- 3) The person a pessimist.

My name is Daniel and I am 13 years old. I, like others, love and enjoy my life. I see the world my own way. I intend to keep it this way. People reading this may think 'oh heck, this kid's crazy'. Do I care?!? God made me the way I am. I've been bullied, name called, pushed, teased, and at what aim. For fun!!!!!! If you think that Autistic children are to blame, check out the people who bullied them! Ever since I've gone to school, life's been hard. I know this because life has been tough to me. I lived through it.

Could you?

So don't be a person who knows what's going on, but is doing nothing about it. Make a difference. Make a stand for those who are different, and make someone's day a happy one.

Enjoy your life. You only get one (in this era anyway!)

Debbie in print!

I have written a mini book about my Mother and the years of devotion, support and understanding.

I have had it published on a self-publishing website (www.lulu.com) It is available on this website to buy. I will receive payment on every copy that is sold. The money will go into my charity account and then from time to time I will give it fund research into the cancer that my Mum died of.

Debbie Hudson

Exclusions

We are increasingly concerned about the numbers of children on the autistic spectrum being excluded from school. The cases coming to our attention range from single or repeated fixed term exclusions to permanent exclusions. Perhaps most worryingly are “informal exclusions” where the school asks parents to keep their child at home, or is failing to meet the child’s needs so significantly that it is impossible for the child to attend school. Children are also being excluded if they are only being allowed to attend school for part of the day, have to be taken home at lunchtimes etc.

We believe that if a child with special needs is excluded from school, it is not the child who has failed, but the school. Exclusion is a clear indication that the child’s special needs are not being met.

The Secretary of State for Education’s guidance to schools says that exclusion should normally only happen: ‘if allowing the pupil to remain in school would seriously harm the education or welfare of the pupil or others in the school.’ In addition, the guidance says: ‘Schools should also make every effort to avoid excluding pupils who are being supported at School Action or School Action Plus.’

If you believe that your child has been excluded as a result of their special educational needs not being met, you may need to consider:

1. Whether the provision quantified in Part 3 of the Statement has in fact been ‘arranged’. If not, you should write to the LA informing them of their failure to fulfil their legal duty to ‘arrange’ the special education provision.

2. Whether the provision quantified in Part 3 is the right kind of provision, or whether there is enough of it. If not, you should write to the LEA asking for an emergency Review of the Statement.

Note: no child should be excluded for a fixed period if as a result they would have been excluded for more than 45 days in that school year.

LEAs have a duty to provide suitable full-time education ‘at school or otherwise’ for children who are permanently excluded from school.

“Full-time” means supervised education the equivalent to that provided by mainstream schools. The LEA should provide suitable full-time education from the sixteenth day after permanent exclusion.

If your child has special educational needs, you can argue that the LEA’s duty to provide ‘suitable’ education means that they have a duty to make provision which will meet your child’s special educational needs.

In addition, if your child has a Statement of Special Educational Needs you can argue that the LEA have a continuing duty to “arrange” the special educational provision which is specified in Part 3 of the Statement, even though your child is excluded from school.

Disability Discrimination

Children on the autistic spectrum not only have special educational needs, they also have a lifelong disability which brings them under the umbrella of the Disability Discrimination Act. The Act makes it clear that a child with a disability should not be excluded for behaviour attributable to their disability. Schools are required to take reasonable steps to accommodate pupils with disabilities. They should

be looking for ways manage the school environment, provide additional appropriate support and seek expert advice, for example from the Autism Outreach teams.

From December 2007 for secondary schools and December 2008 for primary schools, the DDA is strengthened by the Disability Equality Duty: a new positive duty on all public bodies to promote disability equality. This means that, alongside their existing duties, schools and local authorities will have to take proactive steps to promote disability equality for pupils, employees, and service users. They must

Promote equality of opportunity

Eliminate unlawful discrimination

Eliminate disability-related harassment

Promote positive attitudes towards disabled people

Encourage disabled people’s participation in public life

Take steps to take into account people’s disabilities, **even where that involves more favourable treatment.**

Please contact the Helpline if you need advice on exclusion – we are here to help. You will also find excellent guidance and advice on the IPSEA (www.ipsea.org.uk) and ACE (www.wace-ed.org.uk) websites

Lindy Hardcastle

Design a Christmas Card for 2007

For anyone with a diagnosis of Aspergers Syndrome or ASD

You are invited to design a picture for the front of a Christmas card; eight designs will be selected to be printed for Christmas 2007.

Proceeds from the sale of these cards will go to the Leicestershire Aspergers Syndrome Support Group.

- You may use any medium, e.g. pens, paints, collage
- Your design must be A4 in size (21 x 29.7cm)
- Put your full name, address, telephone number, age and diagnosis on the back of your work
- If you would like your work returned, please enclose a stamped addressed envelope

All art work must be received by Saturday 27th January 2007

Send your artwork in a stiffened envelope to:

Shelagh Wilson 9 Knighton Park Road Leicester LE2 1ZA

There will be a £20 gift voucher for each of the eight designs selected, and if your work is selected you will be informed by 1st September 2007

If anyone has any news, views or comments to make about their own experiences, good or bad, we will do our best to include them in the newsletter,

As a general rule, items are published in the next newsletter unless space does not permit, in which case, timebound or urgent items take priority. No items are edited for content unless space does not permit or the contents are potentially litigious. Other changes are made only with the permission of the author.

The views expressed in any article are solely those of the author and not necessarily those of the editor, committee or any other part of the Leicestershire Autistic Society.

Deadline for next edition: 28th February 2008. Items to Lindy Hardcastle (see contacts list) – by e-mail if at all possible.

Autism Exchange

We have recently set up a new website for parents of children with ASD to share ideas and strategies to solve the everyday difficulties which arise from this disorder. We have only just gone "live" and would like to encourage as many parents as possible to post questions to generate interest in this forum. The address is www.autism-exchange.co.uk/forum/. My name is Kate Warner and I am a special needs teacher. and my colleague is Maria Prosser.

Castle Donington

The Castle Donington group (ASPECT) has gone from strength to strength. We have welcomed more families to our meetings during the S.P.A.C.E.. sessions, and a couple of families have regularly joined with the Whitwick activity group on Monday evenings. We have also arranged a regular soft-play session at Jungle Madness in Swadlincote, and once it moves into the new premises in Donisthorpe in December, we will be offered autistic-only sessions. At the moment the cost is £2.50 per child, but this may be reduced if the group is big enough.

Cyril's Nuthut in Long Eaton would also welcome our group and we are hoping to meet there on Tuesdays between 5 - 6.30pm. The cost for this soft-play is £3.50.

Unfortunately, the upper age limit for both sessions is 12 years.

S.P.A.C.E. now meets twice a month on the first and third Saturdays, 10am - 12 noon, at Castle Donington Community College. Parents are welcome to join ASPECT in the community lounge (very informal meeting). £2.50 first child, £1.50 siblings, £2.00 Leisure Link card.

Jane Sherwood (See Contacts list)

Haircut, Sir?

Does anyone know of an autistic-friendly hairdresser for a boy in Leicester? Please call or email Lindy (see contacts list).

100 Club

The 100 membership now stands at 150 – thank you all for your support.

Recent winners are: September -Dawn Craddock, No 10 - £73.50, October-Heike Bowers, No 149 - £74, November – Sue Allsopp, No 141 - £75.

Heike very generously donate her prize money back to the LAS.

I am trying to share out my responsibilities to avoid leaving too big a gap when I retire in eighteenth months. Would anyone like to take over the running of the 100 Club? Please call me if you would like to discuss this.

Lindy Hardcastle

LEICESTER AND LEICS. COMBINED CHILDREN'S CHARITIES ' NEW LOOK' ANNUAL SPONSORED WALK.

Next year the date will be: SUNDAY 29th April - not the usual Bank Holiday weekend. Money is raised for 7 children's charities, the Leicestershire Autistic Society being one of them. This year approximately £3,500.00 has been raised for the Society.

The money has gone towards funding the 'Hearts and Minds' conference held in May, the Loughborough summer playscheme, Haymarket theatre trip at the beginning of December, and to pay for phone calls and other expenses to the Society's own Family Support Worker.

Next year's walk will be a 'FAMILY FUN WALK', and a change of route to the usual one. This is because there are no longer enough volunteers to safely marshall the traditional long route through Bradgate Park and back to Western Park. The new route will start at Western Park as usual but then go to nearby Braunstone Park and back, approximately 3.5 miles in total. This should suit families with younger children as well as busy walkers and those in wheelchairs as well as older walkers. There is only one road to cross, and the walk will take a much shorter time therefore freeing up the rest of the day for other things.

Please make a note of the date in your new diaries and try to support the walk, either by walking or helping in some other way.

All money raised goes towards supporting families of children with asd's.

Please contact me if you would like more information.

Gillian Wisdish (walk committee)

0116 287 6747

JIGSAW COFFEE MORNINGS

These are held on the 3rd Wednesday of the month, DURING TERM TIME ONLY. We meet at the RED CROSS FAMILY SUPPORT CENTRE, Kenilworth Drive, Oadby, Leicester, from 10am to 12 noon.

ALL are welcome, including parents, carers, grandparents, friends and children, to an informal get together and chat with opportunity to meet others. Jigsaw pays for your first drink. There are a large quantity of library books for you to browse through, also videos and other information pertaining to asd's. The facilities at the Centre are excellent for young children, with a ball pool, lots of toys, puzzles and play equipment to explore and toy library which is available free of charge.

There are often speakers at the meetings, and at our next meeting on Wednesday 17th January we hope to have a PAMPERING SESSION.

Transport provided by the Centre may be available if you live in the city, and if not we may be able to organise a lift for you. Please telephone: 0116 271 0359 for the Red Cross Centre.

It would be great to see some new faces (as well as the usual ones of course!)so please come along and join us

JIGSAW SUMMER PLAYSCHEME

For those parents whose children attended the scheme this year, we have now compiled both staff and parents evaluations. If you would like a copy please contact me.

Thank you

Gillian Wisdish 0116 287 6747

Jack's New Option

Many children have already completed their first half term this school year, but very few of them could have enjoyed it as much as one boy with an Autistic Spectrum Disorder.

Jack D'Amore had been out of school for over 4 years since he opted out of his mainstream school in 2002. Jack has a very complex profile and since leaving his mainstream school, 21 'Autistic Specific' schools had rejected him before he settled in at the recently opened, state of the art, New Options school at Barton upon Humber.

Jack's dad, Nicholas D'Amore said "At last, a school can now be named in Jack's Statement of Special Educational Needs. Not only is it a school, but it is an amazing school. The reassurance that I have, is that The Barton School is the right school for Jack. The fact that he went, stayed, has returned home and gone back, is all testament to this."

The pioneering school, which is part of the Options Group, offers up to 26 residential and 4 day places for pupils aged 10-19 with an Autistic Spectrum Disorder (ASD). The service is ground-breaking in many areas, from the design of the building with its specialist indoor and outdoor environments and facilities, to the high quality of care and education.

All of the school's facilities on the fully enclosed site offer the children the opportunity to experience realistic facilities such as the bistro and the cinema in a safe environment prior to and in conjunction with using similar facilities in the local community. In this way, the site enables the children to

develop appropriate skills and facilitates transference of these skills off-site. Some of the facilities that Jack will be able to enjoy include dedicated vocational bases, hydrotherapy pool, sensory rooms, sports hall, games room, sensory gardens, outdoor play facilities and cinema.

Jack is especially proud of his wonderful apartment. There are two self contained apartments which are designed to support students develop skills for independence. The remainder of the accommodation is divided into flats accommodating 4-6 young people.

Each flat has been purpose designed to specifically meet the needs of people with ASD while having a feel of being home. Each flat contains single bedrooms, most of which are en-suite, and have a lounge diner, bathrooms, and a kitchen.

There are several innovative design features in the residential area aimed at enabling children make sense of the world around them. This includes mood lighting and piped music to communal areas helping the young people understand the time of day etc.

In addition to the 26 residential places, The Barton School also has a self-contained family flat with private facilities and separate entrance for visiting parents/carers and professionals.

Nicholas D'Amore said of the new school "The planning, innovation and investment is just beyond belief, it is really breath-taking stuff and I have visited 7 special ASD residential schools. I just know deep down how very lucky I was to stumble on the Options Group's flier in January this year advertising this new development and I also know that Jack will be and is in the right hands."

If you would like to find out more about the New Options school or the linked AALPS college in Scunthorpe that supports 16-30 year olds, please contact Mark Eames on 01652 631280 or marke@optionsgroup.co.uk.

Details of all the Options Group services can be found at:

www.optionsgroup.co.uk

Nick D'Amore writes.....

The road to Barton School has been traumatic, arduous and one that has involved (and will continue to involve) fighting with authority. My thanks go to all those who have unfailingly supported us through the most difficult of times: to our wonderful families (you all know who you are and I and Jack love you all) without whose love and concern I think we'd have sunk long ago and to our loyal friends who've shared laughter, tears, triumphs and disasters.

I am privileged to have met some amazing people who went the 'extra mile' for Jack and who showed faith in us when things were so bleak:

Professor Elizabeth Newson (now retired): Rukhsana Meherali (Independent Educational Psychologist): Peter Parkhouse (Independent Educational Psychologist): Penny Buckle (Independent Speech and Language Therapist): Debbie Onslow (Independent Speech and Language Therapist): Margo Sharp (Independent Speech and Language Therapist): Jenny Wilsdon (Independent Occupational Therapist): Dr. Tom Berney (Consultant Psychiatrist): Naomi Clarke (Deputy Head Teacher at Southlands School in Hampshire)

I also want to convey my thanks and respect to the following band of people who've given everything they could spare in terms of time, encour-

agement and love, as it was all they were able to give. All they could give they gave and it was (and is) very, very much appreciated. These are:

Keith Haywood (past principal of Alderwasley Hall School and registered Expert Witness): Anne Lewis (Autism Specific Family Support Worker) – Anne is funded by both the Jigsaw and Miracles to Believe In charities, and by The Red Cross): and Carol and Catherine Higson (and also to the amazing team of teachers – some who have no formal teaching qualifications) who were able to increase Jack's teaching time at The Leicester Tutorial (based in Oadby, Leicestershire) from one hour per week to over twenty one hours per week just prior to him starting at Barton School).

You are all wonderful, thank you, and if I've forgotten to mention you by name please forgive me as you know I'm a bit of a 'basket case' now.

I was asked some time ago what would be on my 'wish list'. I wished that I could have been given a book eight years ago (that was when we adopted and unwittingly entered the twilight zone of special educational needs) that contained the knowledge that I have now. It would have saved us years of difficulty and heartache. We must seem very stupid parents as it has taken us so long to machete our way through the system and finally access the right help for our son – Jack, but I can assure you that we tried very hard for a very long time. I feel very sad knowing that had we been able to get help earlier, the life of Jack, my life, and the life of my late wife Donna, would all have been very much easier and very much happier.

God bless all the above and all 'carers' everywhere.

Asperger Syndrome Support Group

We had a very encouraging meeting in September from Joseph Mailer of Advance Housing about the options parent have for providing long-term housing with support for their adult children. At the end of a very informative meeting parents went away in a much more optimistic frame of mind believing that their child will get the kind of support and long-term security they supply at the moment. You might want to look at the following website for more information.

http://www.bbc.co.uk/leicester/content/articles/2005/10/20/aspergers_syndrome_ruth_wilson_feature.shtml

In October we had an informative talk from Chris Bush of the new Children's Services department for the county. Chris was able to answer a number of parents' questions and was very helpful when he stayed on giving advice on general issues parent raised when discussing their current concerns.

Unfortunately Elaine Cummins, the speaker on Person Centred Planning was not able to be with us in November but she will join us for the January meeting. I will be sending out details of the speakers booked for 2007 shortly.

Do come and join us on 11 December for our Christmas meeting when we will have an up-date from Anne Lewis on siblings issues. The rest of the evening will be more of a social event with food to share.

Website

Please do look at the website and join in the discussions <http://www.aspergerleics.org.uk/>. Beryl Lymer who has done all the hard work, would be interested to hear if you

think we can add anything else to support parents and carers.

Christmas Cards and Art Exhibition

We will be again holding a Christmas card competition to produce entries for our Christmas cards for 2007. Janie Morgan Wood has put in a separate article elsewhere in this Link-Up. We plan to hold another art exhibition next April at which all entries will be displayed.

This year you can buy cards designed by people with Aspergers Syndrome from the following people:

Shelagh Wilson 0116 270 1074
Central Leicester

Janie Morgan Wood 0116 233 6558
Leicester Forest East

Beryl Lymer who will despatch cards ordered from the website – see above

Julie Harman
01509 889494 or 0777 9593205
Loughborough

Parents in Market Harborough will be able to buy cards from Jasmin Delargy on 07763 823282

It is with great regret that we have to report that Beryl Lymer will be moving house shortly. Beryl has been responsible for setting up the group website and organising the Junior Directory and we will miss her input immensely. This will leave the ASSG committee very short of volunteers and we would very much like to hear from anyone who would like to come and help us develop the support group. Please telephone Shelagh Wilson for a chat. Committee meetings are usually 4 times a year.

XXYY do you know this guy

October 21st and 22nd was the date for the 2nd X/Y Variations Conference at the Babington Technology College Leicester, where 15 families of XXYY guys came from all over the UK to attend from as far as Scotland and St Ives, Cornwall.

As well as having the diagnosis of XXYY Variation the majority of the guys also have been diagnosed with having ASD, Aspergers Syndrome or PDD among others.

Dr Nicole Tartaglia, primary researcher into X/Y variations came from the DAVIS MIND Institute California, USA and gave us a presentation on the effects of having extra chromosomes on the children/adult's body and to also update us on recent research.

It was a wonderful feeling knowing all these families was coming to my home town for this very special event that had taken months to organize, and as they all finally arrived on the Friday evening at the Travel Inn Meridian we all met up for the evening meal at the Beez Knees pub/restaurant just across the road. The manager was pre-warned of our arrival and an estimate of 48 people would require food. Everyone hugged each other and the guys (xxyy age ranging from 4yrs to 32yrs) got on immediately and played just like typical boys (finally meeting true friends). It was great to meet the new families who had joined the UK support group and just as wonderful to see my friends from last years get together. I had to cut the evening short to pick Doc T (as we lovingly call her) up from East Midlands Airport as she had just attended a conference in Ireland. It was so lovely to see her again and I had my

private consultation with her on the journey back and we talked about medication for my son's anxiety and nervousness, ready for the new school he will be attending.

Also attending was Charles Huddlescote from CLASP who offered to be there to give advice on education issues and benefits to the parents, which I knew the parents took advantage of and he was just as busy as Doc T.

Marion (parent) had been working hard with a top professor in Endocrinology from London to encourage the Ethics Committee to fund vital research into the Testosterone side that our guy's bodies are deprived of producing naturally. Three times professor David Russell-Jones put our case to the Ethics Committee and they turned him down on silly reasons to which the professor was furious about to say the least. He will how ever try again in January 07 .

Doc T, is not like any other Doctor we as parents come across; she is so dedicated to all the children/adults and can even name every one of them. All us families have her home address, email address and home phone number in case we need advice about medications or letters of support to be able to get the services our guys need. Do you know of a Doctor that does this?

Well, Saturday arrived and I had arranged for 5 carers to look after the children so the parents could relax and listen to Doc T's talk in the theatre, the college allowed us to use their 12 computers and we also had 3 play stations, videos and DVDs and plenty of creative activities to amuse the guys. The college even provided us with lunch which was wonderful.

In between talks Doc T had been

given a time table organized by Marion (parent) for private consultations to discuss any medications or concerns with their child.

Doc T was on the go from start to finish only taking a breather for lunch, I do not know how she finds the energy to fly around the world giving these presentations and also have private talks with parents.

The parents learnt so much from her talks, finally finding out the reasons behind their sons' behavior and why they are so emotional, the biggest frustration is the Central Auditory Processing Disorder which delays their speech and understanding of the language this is consistent with verbal Dyspraxia and Apraxia (oromotor). Oromotor Apraxia is an inability of the brain to send messages to the muscles of the mouth and tongue to generate movements, expressive < receptive language. They struggle with word finding to express themselves. This was so evident with our youngest guy Lloyd, 4 years, who was using sign to communicate and it was so strange to see how the older guys knew exactly what he was trying to say and helped him just like he was their brother.

They found the talk about sensory seeking and sensory avoidance so interesting too, they found the answer as to why they don't like certain materials rubbing against their skin, why clothes labels irritate them, why they have huge pain when they fall over or fall off play equipment then to find out why they are in so much pain by someone just pushing by them or crying at the slightest scratch.

We also learnt about sensory processing disorder; how the guys have an inability to integrate and modulate the senses, touch, sound,

vision, taste and proprioception (joints and body position) and about volitional component, where they can just do something without thinking (say climbing the stairs) but if they thought about it first they would just stand still and be unable to co/ordinate their feet to climb the stairs.

What actually fascinated me was the new research into how often X/Y Variations happen:

1 In a 1000 babies being born are XXY. Out of 100 in the research program none were in the ASD range.

1 in a 1000 babies being born are XYY. Out of 100 in the research program over 30% was in the ASD Spectrum.

1 in 17,000 are born with XXYY, out of 75 in the research program over 50% had the ASD diagnosis.

Doc T explained to us how at the front of the brain XXY guys don't have anything stopping information going from one side of the brain to the other; whereas in XYY guys a slight protruding wall separating the left and right side of the brain is evident and it is causing the brain to struggle to get the information from the right side to the left or vice versa; but in XXYY guys the wall between the left and right is much more prominent and this is the reason why our guys struggles are greater at learning because this wall is blocking information. This is why we as parents have to repeat or show how to do things over and over again, the other side of the brain is not getting the information so as it is mapped logged and learnt.

This made me realize that even more children / adults are going undiagnosed and struggling through our educational system which means if they don't have a proper diagnosis then their true needs are not getting met.

In one year it is estimated that in the UK 350,000 – 400,000 male births 350 will be born with XXY only 100 get diagnosed, there is no data on XXYY as yet.

But what we do know since Dr Patricia Jacobs who found the extra chromosomes in 1959 based on 3518 males with XXY including 80 with XXYY in the UK have been diagnosed between 1959-2002.

The whole weekend was just so interesting and also fascinating as all the 12 XXYY guys that came along were all so different in strengths and weaknesses but were truly friendly and got on so well it felt like a family reunion and a conference. This was even more evident in the evening of Saturday night when we all got together in the Beez Kneez pub and had one huge game of "killer" on the pool table it was so much fun everybody enjoyed it, not forgetting the guys, they were just so happy to see each other again and played and bonded so well. Something they are deprived of in school situations and even the older guys got on so well.

Doc T was quite overwhelmed by how everyone "belonged" and laughed and enjoyed themselves and the game was finally won by David (XXYY age 18 and 6ft 9") he was thrilled to win £14.

One thing jumped out to me was how all the guys flowed with confidence and not one frustration outburst was seen.

On Sunday it was lovely to see Joseph who was very poorly at last year's get-together. He had flowing confidence and got up on stage and sang us a wonderful song, there wasn't a dry eye in the theatre.

We had plenty of fun doing a raffle of donated gifts. The star prize was a

ps2 speaker system to which the twins Adam and Kane(XXYY 11yrs) were bursting to win, and they did. They were so thrilled, which left David disappointed as he had set his heart on winning it. They both decided to give it to David, a wonderful gesture of kindness.

After everyone taking their photos of each other and the guys, you can imagine how many parents (including dads) cried as we said our farewells.

It was a huge emotional feeling for me all the stresses that come with organizing an event was so worth while and as we hugged and said our farewells for them to take the long journey back to their homes, an experience that they will never forget, that the feeling of being alone is no longer a feeling in their lives.

A truly wonderful time was had by all.

I would like to take this opportunity to say a huge thank you to the LAS for the support they have given me to fund the public liability insurance needed to be able to use the theatre.

Also thank you to Charles Huddlescote from CLASP for using his knowledge to give advice to the parents.

Also to Ann Shellard and Babington College without them there would not have been an event.

The Travel Inn, Meridian for accommodating the families and a very special Thank you to Richard Boucher who for the past year has been dedicated and supportive in helping me to get my son's needs met within the educational system.

Please visit my website www.xxydyouknowthisguy.co.uk

Tina Bale

Reality

Reality holds monthly support group meetings on Thursday mornings from 11:00am to 1:00 pm at the Parkfield School on Pindar Road, New Parks. The date for the remaining meeting for 2006 is December 7th. 2007 meetings are: January 4th February 1st and March the 8th there will be no meeting in April.

No formal diagnosis of ASD is required to attend and anyone is welcome. The meetings are always well attended and everyone is encouraged to participate. Parents can share their concerns or address any issues they may have, with each other, or with any of the guest speakers or visitors from within the ASD community who regularly attend Reality's meetings. Childcare workers are available to entertain your children and members will have access to the toy and book library.

Each year, as a group, Reality provides opportunities for various outings throughout the school holidays as part of its 'pro active' approach to introducing ASD children to social settings. This year included day trips to Drayton manor, Alton Towers, Sundown Park, Skegness and Cadbury's World.

Reality held a charity evening in November, which was again extremely well attended (packed!) and raised over £1600 for the group's funds. Thanks to everyone who donated gifts for the raffle and who bought tickets, and a special thanks to Reality's own star performers; Mel, who opened the evenings entertainment with her own sensational dance routines and Sam, who brought her backing band and sang away everyone's troubles for an hour before the DJ rounded off a night

which had everybody on the dance floor.

The group will be taking the children to see The Wizard of Oz in pantomime at the Haymarket on January 2nd. Other activities for 2007 are yet to be confirmed. Members of the group will be advised as to the dates and particulars of any outings as they become available.

Reality completed a highly successful 12-week course of events at the Outdoor Pursuits Centre near Red Hill Circle prior to the summer holidays, which involved a large number of the children and their siblings from Reality's database accessing archery, wall climbing, abseiling, quad biking and various water sports.

These events have been enormously well received by the children and parents at Reality who have all benefited from the activities. It was really quite amazing to see how quickly most of the children developed their confidence, with the help of parents and the highly praiseworthy and patient centre staff, at what many would regard as quite challenging activities.

Funding has been applied for to continue and to expand the course again next year, as there is already a great interest from many parents about accessing future courses.

Should you require any further information about Reality, or wish to be added to the group's database please contact Leisa Smith on 07879428553 or via e-mail at leisa_smith3@hotmail.com

help and *help2* from the NAS

The *help!* programme is for parents and full-time carers of recently diagnosed children, young people and adults with an autistic spectrum disorder. It aims to provide information, advice and support to help gain an understanding of ASD, ways to support the child / adult, as well as knowledge of rights, benefits and local services. The programme is delivered free to parents. We run a variety of different programmes (a one-day programme, a two-day programme and our 20 hour/6 session full programme) and try to respond flexibly to local need.

To enable us to plan for the year ahead, if you would be interested in attending a *help!* programme in Leicestershire would you please contact us to let us know.

For more information about the *help!* Programme or to register your interest – please contact Lorraine MacAlister 0115 8473538 or email Lorraine.MacAlister@nas.org.uk

The *help2* programme aims to provide parents and full-time carers with information and advice, to support them in the care of their child with an autistic spectrum disorder (ASD) through practical seminars.

Please note that the seminars do not include an introduction to autistic spectrum disorders within their content and, therefore, it is recommended that parents/carers attending seminars already have some prior knowledge.

For more information about forthcoming seminars in Leicester contact Jill Steward 0115 8473532

Sibling Research

Hi there. My name is Lucy Gillatt and I am a Trainee Clinical Psychologist in my third year at Leicester University. I am carrying out a project looking at children's experiences of having a brother or sister with autism. I hope to explore what it is like for children who do not have autism to have a sibling with autism and find out about what their relationship is like with their sibling with autism. Several research studies have looked at how having a brother or sister with autism impacts on siblings, but most of the studies have not involved talking to the children themselves. I am really interested in listening to the views, opinions and experiences of children who have a sibling with autism.

I would like to talk to children who do not have autism aged between 6 and 12 years who have a brother or sister aged between 4 and 16 years who has a formal diagnosis of autism. If you think that your son or daughter may be interested in taking part in my study please contact me either by email at: laeg1@le.ac.uk or by phone on: 07810 375707. Alternatively you can provide Lindy with your details and a preferred way of being contacted email/telephone/letter and I will get back to you. I will be able to provide you with more detailed information and arrange to come and talk you and your son or daughter about the project.

I am very grateful for your help.

ASPIRE: Life-skills

(Autism-Specific Programmes In Real-Life Environments)

In the previous edition of Link-up, ASPIRE (Autism-Specific Programmes In Real-Life Environments) sent out a questionnaire to measure the need and level of interest in its new service – a series of Autism-specific, individualised, Home and Community Life-skills Programmes, to be implemented in clients' homes and local communities. Detailed analysis is ongoing, but ASPIRE is delighted to announce the following results:-

Do you feel there is appropriate and adequate provision for the full range of your son/daughter's present and future needs?

25% YES 75% NO

Would your son/daughter benefit from essential life-skills being incorporated directly into home routines?

91% YES 9% NO

Do you feel your son/daughter would benefit from ASPIRE's Home and Community Life-skills Programmes?

95% YES 5% NO

Would you be interested in more information about ASPIRE's provision?

74% YES 26% NO

The feedback we received has clearly identified a distinct gap in Autism provision in the East Midlands, and highlighted the real need for the service ASPIRE intends to launch in 2007. The ASPIRE team would like to thank all of you who completed the anonymous questionnaires, and assure those who wrote that we will be replying to their letters within the next 2 weeks. For those of you who would like to receive an information pack

(outlining who ASPIRE are, further details of our services, and examples and excerpts of our Home and Community Life-skills Programmes), please call 0870 8966540 or e-mail aspirelifeskills@hotmail.co.uk, leaving your name and address.

The ASPIRE team extends special thanks to *everyone* who has supported us in getting this provision off the ground, and especially the team at Autism Outreach, who have already supplied us with our first contract! Finally, we wish everyone a very Merry Christmas, and a truly Happy New Year.

ASPIRE: Life-skills

(Autism-Specific Programmes In Real-Life Environments)

Loughborough Group

We meet on the last Monday of every month (apart from December, July and August) at John Storer House in Loughborough at 7.30pm. We are a small friendly group who gather for coffee and a chat and would welcome new and old members. Our December meeting was more festive with seasonal goodies brought in to share and we had a talk about Siblings from Anne Lewis. We have had several good speakers over the recent months with Lynda Lowe coming in to discuss how to set up a youth club (which was also attended by several from the Castle Donnington Group) and Charles Huddleston from CLASP. We do not have speakers every month and always find time to discuss any problems we may be experiencing. If you would like a pleasant evening out with no pressure please just come along or ring me on 01530 244790.

Carole Heubeck

Treasurers Report

Many thanks again to those who have donated funds and our fundraisers without whom we could not continue the invaluable work that is done. Kirsty Dawson raised £25 for her cross stitch sales and Mrs Freeman raised £225 for selling Avon. These are two of our regular fundraisers - many thanks, it is much appreciated. We have also received a donation of £50 from a parent who has been receiving the Link-Up for many years and has found it invaluable. They would like it to be used to assist in sending others the Link-Up magazine. We also received £200 through the Charities Aid Foundation which was made as an anonymous gift on the internet - if you read this magazine please accept our grateful thanks. We have also received £700 from the Florence Turner Trust who regularly support our work. Several lucky recipients of the 100 Club have donated part or the whole of their winnings to the society - this is an unexpected bonus that we did not envisage when setting up the fundraiser! Whilst we receive £5 membership fees from our members, this does not cover even the cost of posting out Link-Up to you even without the printing costs which are kept exceedingly low due to the generosity of the UCCF and Gillian Wisdich who compiles them and sends them out on our behalf, if you can support our work by donations or fundraising it would be gratefully received.

We have been exceeding fortunate to have David Hinds who tirelessly works to find funding for our Bosworth Saturday swimming club. We have received £3,000 from the Henry Smith

Charity, £750 from the Sir Andrew Martin Trust and £917.18 from Voluntary Action Hinckley and Bosworth whose area the swimming session is located in. If you have not been yet this is a casual 'turn up' when you want to swimming session for all the family and friends. you can enjoy a quiet fun swim amongst understanding people who are in the same situation as yourself. Give it a go. For more details see the Contacts list.

Carole Heubeck (Treasurer)

Miracles to Believe In

Many of our children love Thomas the Tank Engine and trains and what could be better than a trip on a steam railway? Our last year's trip to the Great Central Railway at Loughborough was such a success that we would like to continue it and run it again this year. We are looking at a weekend in February when the weather is bad and it's a great opportunity to get out of the house. If you are interested in coming along cost only £5 per family - payable in advance, then please contact me Carole Heubeck on 01530 244790 for more details. The ticket will allow unlimited travel all day so while many of us last year just had the one trip, others got off at stations along the route between Loughborough and Leicester to view the miniature railway at Rothley or just to swap trains! You can take a packed lunch if you are staying the day or eat (and drink) in the buffet car or at the pub on the platform at Loughborough. Please give us a ring and come along and enjoy the day either as a individual/family or group!

Carole Heubeck

The Creation Station

New Creative Play Sessions for the under 5s

Mon 20th in the Youth Centre at Rawlins Community College, Quorn, Sessions at: 10.00- 10.50

Starting soon: Tues The Scout Hut, Ashby de la Zouch, Session at 10.30-11.20

Existing sessions

Wed: Loughborough Leisure Centre, Sessions at 9.55-10.45 11.10-12.00

Thurs: Mountsorrel Scout Hut, Sessions at: 10.00 – 10.50 11.10-12.00

Fri: Edwalton, near West Bridgford, Notts. Session at: 10.00 – 10.50 11.10-12.00

For more information call Sarah Cressall Tel: 08456 443 882 or see the website below.

Letters from Santa

Does your child enjoy magical stories written especially for them? Would they enjoy receiving magical Santa post with brightly coloured and illustrated story letters? Our three personalised stories are written and sent the two weeks before Xmas, so the children can imagine the magical preparations that are happening at The North Pole. A great gift for nephews and nieces, god children and grandchildren.

A set of three letters cost £9.99 and include a gift of 'Santa writing paper' to return a picture or story to Santa. Visit the Creation Station web site and click on Santa's letter down the left hand side,

www.thecreationstation.co.uk