



H.A.R.C. Hertfordshire Autistic Resource Centre

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JULY 2006

**The Next Parents Support Group Meeting
THIS WILL BE SENT TO MEMBERS IN SEPTEMBER WHEN THE
ARRANGEMENTS ARE FINALISED
HAPPY HOLIDAYS!**

Parents Support Group Meeting

HARC AGM 14th June

Speaker: Desmond Meldrum

The AGM was well attended and the main business concluded satisfactorily. The HARC accounts were agreed by members and the current Trustees re-elected and Margaret Casey elected as a new Trustee.

The formal motion to wind up HARC and become a branch of the NAS was passed unanimously and we will report on that in subsequent newsletters. Our speaker was Desmond Meldrum who is an adult recently diagnosed with Asperger Syndrome. Desmond spoke about his life, family, jobs, hobbies and interests and then took questions from the audience. It was a very interesting and informative talk giving parents valuable insights into what it is to have Asperger Syndrome and what has helped him in different situations.

Copies of the accounts, chairperson's report, and minutes of the AGM are available from the HARC office.

APOLOGIES

Apologies to members for the delay in the newsletter coming out. It has been an extremely busy term for a number of reasons and I simply did not have time to put it out any earlier.

I do proof read it but have had to type this one up either late in the evening or surrounded by my loving children and their seemingly never ending requests for food etc. So it may not be up to usual standards.

Carol Kelsey

Contact List

Enclosed with this newsletter is the members contact list. This is a list of those members who on their membership form agree for their details to be passed on to other members. Please ensure that you destroy any old lists you may have and **do not pass details on to anyone outside the list**. The list format has been simplified to show only the name of parents, telephone number, town, year of child's birth and whether they are female. This should enable you to contact the parents of a child in your area of a similar age.

Future Support Group Meetings

We are very grateful to Pam Reitemeier who has come forward and offered to organise future meetings and courses. We are working on a number of possible speakers and courses at the moment and we will let you know the programme in the autumn. We are always looking for topics or speakers that members may find useful so please let us know any suggestions you have.

Can you help?

We really need someone who could give up one or two days a month in term time to organise the HARC library. This would mean checking the contents, putting in new books, chasing up overdue books. If you could help please contact Carol Kelsey at the HARC office in September

Closed for the summer

Just to remind members that the HARC office and Helpline are closed during the school summer holidays as we all have our children to entertain. The office will open again on 5th September (don't all ring at once!) and the Helpline on 12th September. The ansaphone and emails won't be picked up until then.

Adult Carers Group

HARC and Carers in Herts held the first meeting of the Carers of Adults with Asperger Syndrome or HFA on 27th June at Trinity URC Church in St Albans. The meeting was well attended by 25 carers who introduced themselves and their caring situation and then split into groups to discuss how to take the group forward and how the group should run. It was unanimously decided to meet in a specified venue rather than moving around and that meetings would be monthly initially but the evening of the week should be varied.

The group wanted to share knowledge and experience, receive advice, raise awareness, increase their own knowledge, campaign for services and as a social group for carers. Jo Willis (Carers in Herts) has agreed to provide some of the admin to ensure the group has a venue, a speaker where appropriate and to write up notes.

At some stage in the future the group will become more autonomous with its own committee.

The next meetings are:-

Wednesday August 2nd 7.30pm at Oxley's Hse, by Hatfield Leisure Centre, Travellers Lane, Hatfield.

Monday 11th September 7.30pm (same venue as above) Speakers will be Mark Jordan Head of Joint Commissioning from Adult Services HCC and Judith Jackson HCC. This is your chance as a carer to say what services you are looking for.

New Parent Carer Action Group

This group is being formed by Carers in Herts for Parent Carers of children/young people 18 and under so that they can have more of a say on services for children with Special Needs and disabilities.

Liz Ranger, Parent Participation Manager at Contact a Family will be talking to the meetings being held on the following dates and venues:
Monday 18th September at St Alban's Children's Centre, Church Crescent St Albans 7.30 to 9.30pm
Thursday 28th September at Ware Priory, High Street, Ware. 7.30pm to 9.30pm
For more information contact Maria Kiely at Carers in Herts on 01442 253344 or email west.team@carersinherts.org.uk

Prevalence of ASD in Herts?

Figures produced by the latest study on the prevalence of autism make interesting reading. The study was reported recently in The Lancet and widely publicised by the BBC and in the press. The figures shown below for Hertfordshire show that we have a significantly increased challenge for Hertfordshire to provide adequate diagnosis and support.

The figures are based on the reported prevalence figures and the Hertfordshire population figures from the census of 2001. A calculation has been used to divide children from adults, as an exact figure is not available from the census. Please note that the numbers do not necessarily add up as each is calculated individually and are based on estimates.

Herts	Children	Adults	People
Classic Autism	900	3000	4000
Asperger and HFA	1,800	6,000	8,000
Autistic Spectrum	2,500	9,500	12,000

Laurence Griffin - Chairperson HARC

Speaking up for autism in Parliament.

Many of us understood only too well what led Alison and Ryan Davies to their tragic deaths earlier this summer. A group of MP's has supported a motion in Parliament on family support and respite services for children with autism and their families. Encourage your MP to sign the motion which calls on the Government and local authorities to ensure that the right services are in place at the time. You can contact your MP through the website

www.writetothem.com you first need to enter your post code which identifies your MP and local councillors and gives a direct link to them. You can check if they have signed the early day motion by logging on to www.theyworkforyou.com

Fitz's Sports Club is to close

After 8 years the HARC Sports Club run by long time HARC member Pete Fitzgerald is to close. Over the past couple of years attendance has reduced and Pete feels it no longer serves the purpose it used to.

There will be one final session on Sunday 24th September at Francis Bacon Sports Centre.

Please confirm attendance directly to Pete on petejifitz@yahoo.com or by phone on 01707 273220 by 8th August if numbers are poor then the session will not take place.

On behalf of Trustees and members of HARC I would like to thank Pete for the hundreds of hours he has given over the years to the Sports Club.

Education Matters

Make School Make Sense

The NAS has launched its first ever education campaign on 23rd May. The campaign aims to improve education provision for children and young people with autism. To find out more and support the campaign go to www.autism.org.uk/msms

Statement Reviews – the child's views.

If your son/daughter has a statement and is coming up for their annual review meeting they should, where able, be asked for their views. One of our members has developed a series of questions that they could prepare in writing or use to prepare orally for the meeting. They have been designed for mainstream school setting but could be adapted for other ages or settings. If you would like a copy the contact the office by email as they are in word file or phone and they can be sent to you. If your child is not statemented but attends an IEP review then they could also be of use.

Exclusions

In the autumn term we will be carrying out a survey of HARC members and those from other Herts support groups on the subject of exclusion from school. We have compiled a questionnaire that we will send to members which looks at permanent and short term exclusion as well as informal exclusion from things such as not attending swimming or school trips.

The statistics and evidence we gather will be used to discuss with CSF to try and improve the situation but of course individual children will not be named. Look out for it and please complete it.

Further resources: ACE (Advisory Centre for Education) has an Exclusions information line 020 7704 9822 (24hr answer machine). They will supply their exclusion pack free to parents Website: www.ace-ed.org.uk

IPSEA (Independent Panel for Special Education Advice) has Exclusion Support Sheets available on their website www.ipsea.org.uk they are very practical and will not overwhelm parents with detail. They also have tips on getting the school on your side.

Managing medicines at school

We do know that parents can encounter problems in getting medicine administered at school. The DfES has produced a document *Managing Medicines in Schools and Early Years Settings*. It sets out a clear framework and explains the roles and responsibilities of parents and carers, governing bodies, head teachers, teachers and other staff.

It can be downloaded from the website free of charge at www.dfes.org.uk (search on managing medicine in schools) or Tel: 0845 600 9506 quoting reference 1448-2005DCL-EN

Source: Contact a Family

IPSEA – volunteer advisors

IPSEA are looking for volunteers to work on their advice line from home. You would receive full training on all aspects of SEN Law and procedures, ongoing support and legal and strategic advice to help with case work for individual families on the Helpline but also for parents who are members of HARC.

This would help HARC improve its local support and advice. Further details from HARC office.

Rathbone

Rathbone is a charity based in Manchester that runs advice lines on special educational needs covering a wide range of issues including Statementing.

SEAL (Special Education Advice Line) 0800 917 6790 Monday to Friday 10am to 4pm

The Asian Advice Line 0800 085 4528 for help in Urdu, Gujarati, Bengali, Punjabi and Hindi.

The email is advice@rathboneuk.org and their website is www.rathboneuk.org

Pro Bono Advocacy

Law firm Herbert Smith has expanded its advocacy work to include acting for the parents of children with SEN. They are working through IPSEA to support parents in appeals to SEN and disability tribunals.

Source: Law Society Gazette.

Post 16 Provision News

We have copies in the office of an article from Network 81 about the new pathfinder project led by the Learning and Skills Council in the East of England. It is designed to bring about a new way for agencies to work in partnership to develop and support post - 16 educational provision.

If you would like a copy please contact the office.

Angela Dyer's replacement

Following Angela's retirement as Senior Advisory teacher for ASD in December 2005 a replacement has been appointed and she started work on July 11th. Her name is Caroline Wells and her role is slightly different to Angela's in that she is the Deputy Head of Advisory services with responsibility for ASD and speech and language. When she has got to grips with her role we hope that Caroline will come and talk at a HARC meeting. Watch this space!

Secondary Transfer

Many of you whose children are going into Years 5 or 6 at school will be thinking about Secondary Transfer. HARC has two home grown leaflets to help you with this - the first is Secondary Transfer which looks at the whole process of choosing a school and then Life at Secondary School which is full of tips to help your child

adjust to Secondary School. Both are written by HARC members who have been through the process. The leaflets are available from the HARC office by email or post and we welcome any feedback or suggestions of things to add or leave out.

They are designed for mainstream schools but have elements that may be useful for special school too. We are able to let members know if another current member has a child at a school you are considering for your child. Please contact the office with the school name and we will check the database for you.

There are 3 NAS booklets that may be of use

1. Working with an AS pupil in Secondary School by Judith Colley Cost £1 (NAS 546)
2. Understanding difficulties during break time and lunchtime at secondary school 50p (NAS 540)
3. Moving from primary to secondary school 25p (NAS 492)

Prices do not include postage. Order from www.autism.org.uk/pubs or tel Central Books on 0845 458 9911

Trampolining is St Albans area

A HARC member would like to take her primary school child to a sympathetic Trampolining session in the St Albans area. If any of you are able to advise then please contact the office so we can pass on the details or your contact no.

Making a complaint

Should you ever need to make a complaint against your local social services department we have copies in the HARC office of a useful article by The Disabled Living Foundation that explains the processes. Contact the office for a copy.

Source: DISH

Pounds for Parents

This is a three year campaign being run by Contact a Family to help families with disabled children claim the benefits they are entitled to. Many families are not claiming the benefits they are entitled to with average incomes in a family with a disabled child around a quarter below the UK average.

If you would like a benefits check then phone them on 0808 808 3555 Mon to Friday 10am to 4pm and Mon 5.30pm to 7.30pm. The call is free and confidential with access to interpreters. Have details of the benefits you already receive on hand when you call.
Source: Contact a Family

HAND goes on-line

HARC has been involved with HAND (Herts Additional Needs Database) since its inception in 2004. It has replaced the old disability register and is there to record the additional needs of children and young people aged 0 to 19 who have long term and substantial conditions that have a marked impact on daily life or who require significant additional care and supervision.

HAND provides HCC with vital information about the needs of these young people in order to improve the planning of services.

HAND also provides families with information about activities and events and the HAND card issued to families can be used to access assistance and understanding and also in some places be used as proof for concessions. HARC strongly recommends that families join HAND which you can now do on-line at www.hertsdirect.org/hand

We have forms in the HARC office if you do not have convenient access to the internet.

We are very pleased that a HAND officer, Louisa Cannon, has just been appointed and this will enable further development. Carol Kelsey attends the HAND steering group which meets termly.

ADD-a-Coach

ADD-vance is a support group for parents of children with ADD and ADHD that meets in St Albans on the first Wednesday of every month. ADD-vance has recently recruited 5 specialist trained ADHD and Asperger Syndrome family support coaches to run courses for families living anywhere in Herts.

The coaches work initially for an hour a week over a six week period with the family usually in their home. Together goals are set for behavioural changes and the coach gives the family the necessary tools to enable the family to achieve them.

The courses are flexible, short term and tailored to the individual families. There are no age limits coaches will work with adults too.

There is a charge of £35 per hour.

For more information contact ADD-vance on 01727 833963

Carers in Employment Project

This project is helping to support Carers who want to return to work or training, need information, have difficulty starting work or maintaining work or who need a financial or benefits check.

You can contact them directly on 0800 028 3699

Talk by Ros Blackburn

Pinewood MLD Secondary School in Hoe Lane, Ware is hosting a talk by Ros on Monday 18th September at 7pm.

Ros is a woman with High Functioning Autism whose talks give a fascinating insight into her world using humour and graphic examples of her own experiences.

The talk is not suitable for young children. Tickets are £5 each and available from Pinewood School on 01920 412211, ask for Maria Fuller.

London to Paris Bike Ride

In aid of the National Autistic Society 18th to 21st May 2007

This fundraising ride will cover the 300 kilometres from London to the Eiffel Tower in Paris in 3 days. Anyone interested in taking part should contact Maribel or Natalie at NAS on 020 7903 3529 or email fundraising@nas.org.uk

Getting a Passport

Strict new rules on how a passport photo should look have resulted in problems for the families of children with various disabilities of getting their photos accepted. Contact a Family (a charity representing all disabilities) would like to hear from you if you have had problems with this as they are making representations to the passport office. Contact them on Helpline@cafamily.org.uk or phone 0808 808 3555

Free travel on London buses

Young people under the age of 16 can now travel free on London buses and trams with the Oyster child photo card. You also get cheaper travel on the tube and Docklands Light Railway. Children under 14 do not need the Oyster child photo card to travel free.

Application forms for the photo card are available from Post Offices in the Greater London area where they should be returned in person with an original passport or birth certificate, a recent passport photo and a one-off payment of £5.

Further information is available from the Oyster Child photo card general inquiries line 0870 443 1044. Source: Jigsaw Magazine

Special needs toys

TFH has been developing Special Needs Toys and Equipment for 20 years. They offer carefully selected fun products designed to help children with special needs enjoy life and achieve more.

Website www.tfhuk.com/caf.asp

Of phone for a catalogue 01299 827820

Source: Contact a family

Holiday breaks at Jubilee House

Jubilee House is a well established provider of services to children and adults with learning disabilities, delivered in a purpose built five bedded bungalow in Welwyn Garden City.

They have recently begun to offer one week holiday packages for a maximum of 4 children.

Places can be purchased through HCC of private funding. If you would like more information contact Amanda Mair, Jubilee House Care Trust on 01707 390107 (ext 25) or by email on

amandajmair@yahoo.co.uk

Football session in St Albans

St Alban's City Youth Football Club has started a Disabled Football section. The Club has a Disability Development Officer, Daniel Rogers who aims to help more young disabled people into football and to enjoy themselves.

Training is every Friday from 7pm to 8pm at St Albans City Football Ground, Clarence Park, St Albans. Contact Daniel on 01727 873479 or email info@cityyouthfc.com

Website www.cityyouthfc.com

Source: DISH

Special needs swimming sessions

Borehamwood Otters - this club meets every Saturday between 4.30pm and 5.30pm at Borehamwood Swimming Pool in Elstree Way. The session is free and supervised. For more information contact Pat Brown on 020 8207 6521 or George Male on 020 8953 5231

Source: DISH

Harpenden Pool - Every Saturday at 3pm, £2 a session.

Little Otters at Townsend, St Albans- the session is on Thursdays from 5.15pm with a swimming teacher approx £45 per term.

Source - HOPE

Donations to HARC

We have been extremely fortunate to receive some donations over the last few months:-

The Institution of Lighting Engineers London and South East Region donated £350 raised from their after dinner raffle. Thank you to all their members and to Chairman Allan Howard for arranging it.

Christopher Griffin raised £133 from his colleagues at Fortune Technology by being silent at work for a whole day! Thank you Chris.

The King's Arms, King St, Tring donated the proceeds of their pub quiz league held over 11 weeks to HARC. This was the magnificent sum of £2,000. Laurence and Ann Griffin attended the King's Arms in person to accept the cheque on behalf of HARC from Vicky the landlady and having sampled the real ale Laurence can recommend a visit to the pub if you are in the area!

Other Helplines

The Contact a Family Helpline is now open every Monday evening from 5.30pm to 7.30pm.

The freephone Helpline gives information on all aspects of caring for a disabled child - whatever the disability- such as benefits, assessments and SEN statements. Tel: 0808 808 3555

OASIS Office for Advice Assistance, Support and Information on Special Needs has a new Helpline number charged at standard BT rates 01590 622880 manned Monday to Friday 1.30pm to 4.30pm

The Yoropen

This is a new inexpensive pen, developed by the father of twin girls with learning difficulties.

The pen is designed to make writing easier as the pen has a triangular grip, an angled nib and can be held at a more comfortable angle (rather than upright). The writer can see the letters form as they write. They cost £3 for two and are widely available from stationers.

Source: Good Housekeeping April 2006

Thomas Zip pulls and Bookmarks

To help raise funds the NAS has a new range of zip pulls including Spencer, Emily and Harold and also bookmarks that are available to buy through the NAS. For more info visit

www.autism.org.uk/thomas

Writing a Will

What will happen to our children when we die is something none of us like to think about but have to. The NAS, in response to the many enquiries they receive from parents on this topic, have produced a booklet 'Guide to wills and trust' that is available from Jason Bowles on 020 7903 3650

We also have material published by Mencap on the same topic and a list of Herts solicitors who have experience of drawing up wills and trust for families such as our. Please contact the HARC office for more information.

Source: NAS and Mencap.

Information & Publications

The NAS Information Centre

The Information Centre maintains Autism Data, a database of over 15,500 articles, books and videos on autism including Asperger Syndrome. They also offer a free enquiry service providing customised reference lists from Autism Data. Information sheets are on the website www.autism.org.uk/infosheets or may be obtained from the Information Centre. Information packs for students or different professions can be requested. There is also a Reference Library available by appointment only. The Information Centre can be contacted by email on info@nas.org.uk or by phone on 020 7903 3599.

National Autistic Society

'How do you feel Thomas?' This new book from Egmont UK and HIT Entertainment focuses on understanding facial expressions and emotion. It

is £5.99 (NAS receives 30p per book sold) and is widely available.

New NAS publications catalogue available now!

All NAS publications can be seen on the website and a catalogue requested or books ordered on www.autism.org.uk/pubs Phone for a catalogue on 020 7903 3595 NAS members receive 10% discount. HARC has some catalogues that will be available at meetings for members.

Publications include:

'My sister is different' by Sarah Tamsin Hunter which is about the ups and downs of life with a sister with autism.

There are other titles for brothers and sisters. ALSO 'Going to the dentist: a guide for people with autism and Asperger Syndrome.'

'Patients with autistic spectrum disorders - information for health professionals.'

'Supporting students with Asperger syndrome in higher education'

'Bullying and how to deal with it: a guide for pupils with ASDs.'

'Moving House' and many more!

Asperger Guides from Lucky Duck

These guides are written by Genevieve Edmonds and Dean Worton and are for adults with Asperger Syndrome.

The titles are 'The Asperger Love Guide'

'The Asperger Social Guide' and (from October 06) The Asperger Personal Guide.

They can be ordered from SAGE publications on 020 7324 8500 or post free on

www.PaulChapmanPublishing.co.uk

We have order forms with more details in HARC office.

Jessica Kingsley Publishing - catalogue and new books.

We have a large number of their latest catalogue of books related to autistic spectrum disorders.

They will be at meetings or can be requested from the HARC office.

Books include:

1. The Autistic Spectrum and Further Education:
2. A Guide to Good Practice - Christine Breakey
3. Friendships the Aspie Way - Wendy Lawson
4. Social Skills Groups for Children & Adolescents with AS: a step by step programme - Kim Kiker Painter
5. Working on the front-line with young people with autism - Matthew Hesmondhalgh

The views expressed in this newsletter are not necessarily the views of the HARC committee

6. DVD - Introduction to Asperger Syndrome - Simon Baron-Cohen
 7. Practical Socialisation Techniques for Adolescents with AS
 8. Tips and Strategies for Parents and Carers of Children on the Autistic Spectrum
 9. Encouraging Appropriate Behaviour for Children on the Autistic Spectrum
- Further details of all books on website

www.jkp.com

Living with Aspergers DVD

Members of ASGMA (Autistic Society Greater Manchester Area) talk about life with Asperger Syndrome giving a fascinating insight into the difficulties they encounter and how they cope. Copies are £8 each available from ASGMA, 1114, Chester Rd, Stretford, Greater Manchester M32 0HL (Cheques payable to ASGMA)

Website: www.asgma.org.uk/index.html

Source: Positive Aspects

Downloads

Learn with Kevin Early language stories developed by a parent. The stories use photos to illustrate concepts. Each pack has a story accompanied by two or more activities. www.widgit.com/resources/communication/kevin/index.htm

Websites

The NAS have added a new area to their website called 'Diagnosis' www.autism.org.uk This aims to provide useful information and advice to parents of children who have recently been diagnosed, people who have just received a diagnosis themselves and those who are considering getting a diagnosis.

Positive Aspects - this is a new email only newsletter for anyone with an interest in disability, mental health issues and/or illness and is put together by Trudy Ransome a parent of special needs children. To subscribe email her on trudy.1@ntlworld.com with subscribe and the county name in the title and she will do the rest.

Carers in Herts new look website - this organisation supports and represents carers across Herts and all ages groups the new website is www.carersinherts.org.uk

Language info - The NAS is one of the advisory partners in the Parent Point project. Parent Point, launched in May, gives parents information on all aspects of children's communication development and disabilities, giving them the

knowledge and resources to support their children's communication development.

Visit www.talkingpoint.org.uk

Research help wanted

Fathers of a child with an ASD are needed by Nicola Burns, an autism therapist, who is undertaking research for her MSc into the impact on Fathers of having a child with an ASD. This is an overlooked area of research so if you would like to support her please contact her directly on nlb3477@hotmail.com to enroll and receive the questionnaire.

Source: K McDonagh, Pheat.

Language Research - Researchers at Reading University are looking for the parents of autistic children in the early stages of learning to speak (using single words), who are willing to spend about 15 minutes filling out a questionnaire on their child's language. The results will help to identify word learning patterns in the children. Individual results will remain confidential.

To help, contact Kim Freeman on 0118 378 7552 or email k.m.freeman@reading.ac.uk

Recognising emotions for young children with Asperger Syndrome or High Functioning Autism Yael Granader of the Autism Research Centre at University of Cambridge is looking for children with the above diagnosis who could help evaluate the effectiveness of an animation series The Transporters. It has been created to help young children learn to recognize emotions.

Participants receive a copy of a DVD of the series and asked to commit to watch it for 15 minutes a day over 5 weeks. For further details please contact Yael directly on 01223 746030 pr email yeg20@medschl.cam.ac.uk

The Autism File Post 16 Research Project

The Autism File (an autism biomedical publication) is looking for the real life experiences of autistic children who are over 16 to look at what the future holds for autistic children. They want views and private opinions on a wide range of issues such as education, parental support, local authorities, and training for professionals. For more information contact Polly Tommey on 020 8979 2525, email info@autismfile.com or visit www.autismfile.com/

Source: Positive Aspects