

RESEARCH AUTISM

Improving the quality of life



Issue 2

June 2006

Dear Supporter,

We have had an exciting six months since we sent you our last newsletter and have made significant strides forward with a number of projects. We hope you enjoy reading about our progress – and all the further developments we have in store.



First collaborative autism research forum

Sleep issues in autism



Professor Pat Howlin, Richard Mills, Dr Jeremy Turk, Dr Luci Wiggs, Jacqui Jackson, Professor Chris Cullen



Research Autism's collaborative research forum on sleep issues in autism brought together individuals with autism, parents, professionals, researchers and funders on 25th April.

We are hugely grateful to BUPA, the event's sponsor, and to London South Bank University, who provided their excellent facilities free of charge, for making this event possible. And of course thanks go to everyone who attended for their participation and helpful feedback.

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Sleep issues in autism *(continued)*

'a very informative day. The mix of individuals was especially useful...'

A key aim of Research Autism is to connect those affected by and interested in autism in order to improve communication, stimulate collaboration and provide momentum for research in the areas of greatest need in autism intervention. Our research fora are designed to do exactly this.

'this is such a desperate issue for our family'

'loved it – thank you for helping families like mine'

'Sleep issues in autism' was received exceptionally well. The topic was chosen as one of the key areas of concern highlighted in responses to our 2005 survey of the National Autistic Society (NAS) membership, conducted by Richard Mills and Lorna Wing.

'very good and high level discussions and debates throughout the day'

Dr Luci Wiggs presented work on behavioural approaches and Dr Jeremy Turk spoke about drug-prescribing for sleep problems and also on the use of melatonin. Jacqui Jackson gave a very informative talk on her family's practical experience.

Workshops were then held to enable delegates to discuss the issues, share practical tips and – extremely importantly – to come up with suggestions for future sleep research projects and possible collaborators.

'more please – excellent'

Research Autism is now working to define a research project based on the outcomes of the day. Details of possible subject areas and progress can be found under 'Collaborative autism research forum' in the research area of our website at www.researchautism.net.

'we would value future research on other practical issues'

We remain focused on issues that are of particular importance to individuals with autism and their families and are committed to collaboration to achieve this. Our study of the NAS membership continues to provide guidance for Research Autism as we consider our future projects. Issues that affect quality of life will continue to have highest priority.

Our next forum will be held in London in the autumn on '**Successful futures for adults**'. This will look at the issues faced by people with autism in adulthood and will include models of care, housing and support and access to employment.

If you would like a place on our waiting list for the event, please contact Sarah Chivers at sarah.chivers@researchautism.net or at Research Autism, Church House, Church Road, Filton, Bristol BS34 7BD giving your name, role and organization if relevant, and brief description of your interest in autism.

Study weekends

Research Autism is hoping to organize study weekends around the UK in the future to develop understanding of autism and the ways of helping those affected.

More details about these events will be available soon, but we would like to hear now from people with autism, families, professionals and researchers

who might be interested in participating. Please express your interest by contacting Sarah Chivers at sarah.chivers@researchautism.net or at Research Autism, Church House, Church Road, Filton, Bristol BS34 7BD giving your name, role and organization if relevant, location and a brief description of your interest in autism.

On-line autism information centre . . . coming soon



The development of our website as an information hub giving comprehensive, impartial information on all interventions in autism is on track for public launch in early 2007.

The site will contain information about common interventions, what they are supposed to do and whether or not there is any scientific research to back up the claims made for them. This information will be presented at three different levels, allowing visitors to choose how much detail they wish to see.

The site will also contain information about the different forms of autism and about some of the common problems facing people with autism - such as sleep disturbance.

Our thanks continue to go to BT and the Gatsby Charitable Trust for their support of this invaluable work.

Appointment of Information Manager



Bernard Fleming has joined us to lead the Information Centre project. Bernard has worked most recently for the Mental Health Foundation and previously for the RNIB and has spent almost twenty years developing and delivering high quality information services for disadvantaged communities. He is an award-winning website manager with ten years experience of running and developing high-profile websites, including the largest websites on mental health and on learning disabilities in Europe. We are delighted to have him as part of the Research Autism team.

Please tell us your story

We want to know more about how treatment issues have affected people with autism. Life stories will assist us in raising funds so we can do even more to help.

Stories might relate to getting a job, to particular problems concerning behaviours, to sensory problems, to helpful treatment approaches, to successful or unsuccessful residential options, to unhelpful or misleading treatment approaches, to lack of information or guidance on the approaches out there . . . and so on. Personal stories can be made anonymous if people wish, but it is the detail that is so important.

If you can assist us by sharing your personal experience, please let us know by contacting Emma Osler (details on back page).

Comment

In the last edition of this newsletter the Chairman reported on the death of a child with autism who was undergoing Chelation Therapy. Research Autism has been advised that this death was as a consequence of how the procedure was administered. Naturally a great deal of concern has been generated throughout the autism community and the media and there are requests for more information about this particular treatment. At the time of writing there is no good evidence about this form of intervention but Research Autism is giving this priority as we compile our on-line information centre.

Research project update

Sleep

A number of important areas for research on sleep issues were identified at our research forum on 25th April. These include issues for families, behavioural interventions, medication, including melatonin and prescribing protocols, effects of services, including respite, genetic factors and sensory issues. Research Autism is organising a follow up meeting with researchers to take these issues forward. Progress will be noted on the research area of our website (www.researchautism.net) and, of course, we will update you in the next newsletter.

Bullying

Richard Mills, Research Autism's Research Director, has been instrumental in two research projects looking at Asperger Syndrome and bullying – Professor Digby Tantam's at the University of Sheffield and Dr Neil Humphrey's at the University of Manchester - joining forces. The combined project, led by Professor Tantam, seeks to establish whether in mainstream secondary school pupils with Asperger Syndrome / high functioning autism are bullied more or less than other pupils and in what ways. This will help to identify more effective methods of intervening. A pilot study is to be funded by the Inge Wakehurst Trust.

Prison survey

Seminars are planned with prison staff in the Midlands and Scotland with a view to designing a screen to investigate the prevalence of autism in prisons. This screen will then be tested and applied and we are hopeful this will have a wide relevance to the prison service and that we can influence a thorough review. We are grateful to our colleagues, Professors Cullen, Brugha, Howlin, Johnstone and Dr Crocombe, who have so generously given their time to work with us on this important project.

Diet

We are seeking to investigate the impact on social and communicative behaviour of excluding gluten and/or casein from the diet of preschool children with autism. The project has been separated into distinct stages. We are grateful to the Cadbury Schweppes Foundation for funding which will be used to translate hard copy questionnaires into a robust web-based format for use in the trial. We will be embarking soon on the development of challenge foods for this work. Autism Speaks (previously NAAR) continues to take a joint interest in this study.

Edinburgh marathon



Our 38 Edinburgh marathon runners last year raised a stunning £20,000 for Research Autism's work. As we go to press with this newsletter, 80 runners are limbering up for this year's marathon on 11th June.

We are bowled over by the support we have received for this fundraising event. The Southampton Childhood Autism Programme, one of the major projects which Research Autism is backing, is fielding no less than seven runners. There has also been great enthusiasm from companies for the five-person marathon relay event. We have groups from Redleaf Communications, Saxton Bampfylde Hever, The UNITE Group and Goldcrest Homes and are sure they will join last year's runners in finding this a fantastic team-building

experience. Thanks also to Edinburgh Psychiatry and those teams made up of friends and family.

Sponsorship money has been coming in fast already. We are extremely grateful to everyone involved and are looking forward to a fun-filled weekend. Once again, Glenmorangie is generously sponsoring us, providing Research Autism running shirts and whisky prizes.



Next year's race and other fundraising events...

Please contact **Emma Osler** (see details on back page) to enquire about running for Research Autism in next year's Edinburgh Marathon. We would also love to hear from you if you would like to support us through sponsored involvement in any other event. We can provide support and further information about the charity. Please get in touch!



Southampton Childhood Autism Programme (SCAmP)

The team at Southampton University is well underway with the assessment phase of this study, aimed at gaining a more complete understanding of the effects of early intervention. Children involved in an initial study on the effects of home-based Early Intensive Behavioural Intervention (EIBI) are being followed up two years on, after two years in school.

We are grateful to the Esmee Fairbairn Foundation for funding this major part of the project and are now seeking further funding for final analysis due to take place at the end of this year. Wide dissemination of the results is planned through scientific journals and the websites of the University and Research Autism.

Work preparation

This is a three year study of the impact of interview and communication skills training on job success for participants with autism. The training is to be provided by Manchester Business School with evaluation conducted by Liverpool John Moores University. We are still in discussion with the Department of Work and Pensions about funding for this work.

There is obvious synergy between this project and the work of Prospects Employment Consultancy, part of the National Autistic Society, which helps adults with Asperger Syndrome find and retain employment. We

will therefore be working in conjunction with them to raise funds and awareness in the Manchester area for this project and their work. Bruce Thompson, Acting Head of Prospects, said 'This is an important area of work and we are delighted to work closely with MBS and Research Autism in developing this course'.

Drama

This project, looking at the effect of drama on social skills and self confidence, is now under way. Daisy Loyd is undertaking preparatory work at The Sybil Elgar School in Ealing and Heathermount School in Surrey. Our Research Director, Richard Mills, is monitoring this project closely with the Institute of Education. We are grateful to the ESRC for their support and to Chloe Phillips of the Sybil Elgar School and Stephanie Lord of Heathermount School for their enthusiastic input.

Learning Environments for Children with Autism (LECA)

The LECA project is now at the design and test stage. Rob Burn, the project leader, is working with designers to conclude the specification of the equipment, which will facilitate and maximize learning opportunities for students with autism. LECA is working closely with the NAS Radlett Lodge School in Hertfordshire and with Sunfield School in the West Midlands on the project specification. We are grateful to the Three Guineas Trust for their support of this project.

Recycle your mobile phone

Research Autism is working with Carphone Warehouse to recycle mobile phone handsets for charity. We will receive £9 for every handset we recycle. Most of us have a couple of unfashionable handsets hidden away at home. Why not reduce your clutter and contribute to charity at the same time? We will soon have recycling bags and collection points to drop your phone at, but even before these are ready, we can start collecting phones to help fund Research Autism's work.

Please post your old phones to Research Autism, PO Box 49650, London N8 9WW or hand them to staff at Research Autism events. If you are a company who might like to support us by donating old corporate phones, or galvanizing your workforce to bring in old handsets from home, we would be particularly keen to hear from you. Please contact **Emma Osler** (see details on back page).

Is it your birthday? Are you getting married?

Maybe you're hoping for some special presents...but perhaps you already have everything you could possibly want. Would you consider asking friends and family in lieu of giving presents to donate to Research Autism to support our much-needed work? Please ask **Emma Osler** (see details on back page) for further information.



Christmas cards

It seems a little early to be thinking about Christmas, but please do bear in mind that you can get your Christmas cards, when the time comes, from us. Information will be posted on our website soon, or contact **Emma Osler** (see back page for contact details).

A powerful team

We would like to express our gratitude to all members of the Research Autism team and to all our advisers, supporters and funders.

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Mr Geoffrey Maddrell (Chair), the Unite Group
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Dr Vicky Slonims, Guy's Hospital

A few words from Research Autism's founding Chairman

We are delighted to be able to report progress on so many fronts and are confident that we are well on our way to addressing the gaps in information and research in the area of autism interventions.

As Research Autism's activity increases exponentially, we are guided by two core themes: responding to need as expressed by those affected and collaboration.

We continue to be led by the specific needs expressed by those affected by autism and their families. We are dedicated to the development of our on-line information centre on interventions as a resource which parents have told us they are crying out for. And our priorities

for research continue to be centered on areas of need highlighted by families.

In terms of collaboration, our first research forum is particularly worthy of mention as a wonderful event not only for the research it will stimulate but also for the very fact that it brought together so many different groups with an interest in autism intervention. The more we can work together, the greater our impact and usefulness will be.

We continue to enjoy a supportive relationship with the National Autistic Society and are thrilled that Research Autism's work may be a focus for their 2008 international conference, one of the world's major conferences on autism.

DONATION FORM

Making a difference

A very effective way that you can help us to continue our vital work is by making a regular donation to Research Autism each month by **Direct Debit from your bank account**. Your regular donation can help transform lives. We will make sure that your donation is spent wisely and where it is most needed.

To donate regularly or make a one-off donation, please use the form below, call the Research Autism Donation Line (0117 974 8400) or visit the 'donate' page at www.researchautism.net.

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Staff

Richard Mills, Research Director and Honorary Secretary
Sarah Chivers, PA to Richard Mills
Bernard Fleming, Information Manager
Deborah Higgins, Volunteer Fundraiser
Roger Maingot, Volunteer Administrator
Emma Osler, Development Executive



As always, we remain focused on our vision of: *a world where those on the autistic spectrum are able to realise their full potential and where they and their families are able to enjoy a good quality of life*

We look forward to keeping in touch with you.

Yours faithfully

Geoffrey Maddrell

1

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Surname	
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2

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Bristol BS34 7BD

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To the Manager (Bank/Building Society)

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Please pay Research Autism Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with Research Autism and, if so, details will be passed electronically to my Bank/Building Society.

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Date

3

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Research Autism would like to update you from time to time in order to inform you about our work. If you do not wish to receive any mailings from Research Autism, please tick the box

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RESEARCH AUTISM

IMPROVING THE QUALITY OF LIFE

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If you would like to know more about Research Autism, please visit our website at www.researchautism.net or contact:

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