

Dom's Fund

*The Royal Hospital School,
Holbrook was the venue for
The Trust's Open Evening*



Back to School

More than 170 supporters joined The Trust at its Open Evening held on 9th October 2008 at The Royal Hospital School, Holbrook. After an update on research carried out at the UCS by Dr Penny Cavenagh and Research Associate Sarah Costelloe, the keynote address was given by John Bercow MP, now Speaker of the House of Commons (pictured below, second from right).

John Bercow had been asked by the Government to chair a report making recommendations about what steps it should take to transform provision for, and the experience of, children and young people with speech, language and communication needs and their families. He presented his findings, which emphasise the imbalance of communication between professionals; the importance of early identification and intervention; the need for a continuum of services and multi-agency collaboration; and consistency and equity of access for families to SLT support. More information can be found at www.dfes.gov.uk/bercowreview.

Eleanor Barker replied on behalf of the Fund, demonstrating how the work of the Fund was addressing each of the principle concerns expressed in the Bercow Review. For more information, visit www.dominicbarkertrust.org.uk.

The evening was informative and provided for guests to meet over an informal supper and The Trust is truly grateful to Gill Garnham for all her hard work. It also prompted a number of generous donations for which the Trustees are very grateful.



Trust signals support for ACCE

Eleanor Barker, Vice Chairman, represented the Trust in June 2009 at the All Party Parliamentary Group (APPG) on Speech and Language Difficulties, which saw the launch of an initiative called the Adult Communication Coalition (England) (ACCE).

Previously chaired by John Bercow until he became Speaker of the House of Commons, it aims to build on the Bercow Review and to campaign to have a similar outcome for adults as the Bercow review is having for children.

The ACCE is a coalition of charities, many of which are campaigning on

acquired speech and language difficulties in adults (caused by disease, ageing or trauma), and only a few on innate conditions such as stammering.

In the short term, ACCE is pressing for a Government audit of services for adults with speech, language and communication needs (SLCN), and looking for evidence of their needs that can become the basis for commissioning of future services.

The Trust will support the campaign and share findings of its research to assist in the development of future policy through this group.



View from the Chair

Welcome to the latest Newsletter from the Dominic Barker Trust.

This newsletter highlights some of the most recent practical progress that has been made to improve the lives and experiences of people who stammer through the work of the Dominic Barker Trust, which has now been funding projects for the past 11 years.

It is particularly important for us to continue to work in partnership with other organisations, including academic institutions, and to date we have worked with the Suffolk College, University Campus Suffolk (UCS), the University of East Anglia (UEA) and Leeds Metropolitan University.

Current and future research activities will, we hope, build on the outcomes and successes of previous work and deepen our understanding of the causes of and treatments for stammering.

Crucially, the Trust also works with those at the other end of the spectrum, offering professional activities and advice days for the speech and language therapists (SLT's) who provide the support and treatment which people who stammer, along with their families, so vitally need.

Much of the work we have supported has been in East Anglia, which we hope will become a centre of excellence. The work has been funded with the generous contributions that you have so kindly donated and we are enormously grateful to all of those who have given in the past and continue to give. Your support is essential to the continued work of the Trust. We thank you most sincerely and please continue to support us to fund this important work.

Toby Kramers, Chairman

Spreading the word

News from the University of East Anglia (UEA)

Tamara Davidson Thompson – holder of the Dominic Barker Trust studentship at UEA – is writing up her thesis, having completed the third year of her PhD, under the supervision of Dr Jan McAllister.

Tammy's work has already attracted considerable attention in the dysfluency community. She has made a number of presentations including to the Royal College of Speech and Language therapists conference and at the Oxford Dysfluency Conference (see page 4) entitled 'Is current speech and language therapy practice meeting the psychosocial needs of adults who stutter'. Her findings have also appeared in *SIGNAL*.

In her paper published in the *International Journal of Speech-Language* in February 2009 entitled 'Evaluation and

discharge criteria in therapy with adults who stutter: A survey of speech and language therapists', Tammy concludes that current practice amongst this group of speech and language therapists is very varied when dealing with people who stammer. She says that her research has shown that while there are some excellent elements of practice, other clinicians do not appear to be adequately equipped to work successfully with this client group. Diverse training, service provision and resources also affect the type of therapy that clients receive. Tammy's study was exploratory and it has established a framework for further research that will allow a fuller investigation of evaluation and discharge criteria.

Further information on this paper –



Tammy Davidson Thompson (above) and Dr Jan McAllister



which was co-written with Jan McAllister, Malcolm Adams and Simon Horton, all UEA – can be found at: www.informaworld.com/smpp/content~content=a907764246~db=all~jumptype=rss

On the personal front Tammy has also been busy and the Trust congratulates Tammy and Rob on the safe arrival of Matthew on 18th March this year!

Early learning

An Update on Research at University Campus Suffolk (UCS)

Research Associate Sarah Costelloe is being funded by the Trust at UCS, and supervised there by Dr Penny Cavenagh, in an Early Childhood Dysfluency Project, which is focusing on those factors which may influence long-term dysfluency.

This long-term project will follow the experiences of 40 dysfluent young children referred by GPs, speech therapists and health visitors in Suffolk along with a control group of 40 other fluent children. While it is an independent project, it is being conducted with the collaboration of Dr Steve Davis of University College London (UCL), who is carrying out similar research with older children.

Main picture: Research Associate Sarah Costelloe with one of the project's participants
Right: Dr Penny Cavenagh



COMING UP

Dr Per Alm of the Department of Neuroscience, Uppsala University has prepared for publication, with funding from the Trust, a review on temperament and stammering and also an article 'Updated theoretical model of stammering, with focus on the brain'.



Suffolk-based SLT Isobel Pickering has carried out four studies (aided in one of them by SLT Fiona Hamilton) funded by the Dominic Barker Trust writes Trustee Chloe Chancellor. Their paper on 'The Effects of Play Situations on the Fluency of Children who Stammer' was well received at the 5th Fluency Association Congress in Dublin in July 2006. The Trust is delighted to support Isobel in building on this important work with a further research project called 'Start/Stop'.

"This is an exciting opportunity," says Isobel, "to investigate the impact of a home-based programme for young children who stammer."

The project essentially tests the efficacy of a particular way of supporting parents and carers to help the dysfluent child at home before therapy becomes available at a clinic. The idea is grounded in previous research and clinical knowledge about practical and fun ways to help children who stammer.

Young children spend most of their time at home and it is the most natural environment in which to practise speaking. Home-based activities, therefore, tend to give good results. The Start/Stop Project will provide parents with a ready-made resource and directions for working constructively with their child's speech.

"All the parents have to do," says Isobel, "is open the box every day, choose



Making a start

New Stop/Start project

Isobel Pickering interacts with one of the children

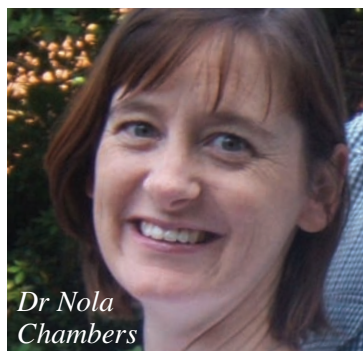
an activity and follow the instructions in order to get their child speaking more fluently. I am hopeful that this project will help and empower parents to manage their child's speech in their own homes and will have a positive effect on their child's speech fluency."

Grants from the Suffolk Foundation, the Grimwade Trust and the Tanyard

Trust will help greatly with the purchase of appropriate equipment for this study. Isobel is currently working hard to refine all details of the project and get the research underway. She plans, with the support of research assistant Rachel Pennick, to begin data collection in January 2010. The Trust awaits their results with great anticipation.



Monica Bray



Dr Nola Chambers

Freedom of speech

Evaluation of TAD

Monica Bray and Sarah James, of the Leeds Metropolitan University, have completed their evaluation. The study, funded by the Trust, was published in the *International Journal of Speech-Language Pathology* in February 2009: 'An evaluation of a telephone assistive device (TAD) for people who stutter'.

Monica concludes, "This study took place in natural, rather than laboratory settings and used real phone calls as its data. It provides evidence that it is beneficial for some to use a dedicated device in a speech situation that is of particular difficulty, such as the use of the telephone".

The Trustees hope that Voice-Amp's Alan Falck, who developed TAD, will use the information to improve technologies especially for the use of TAD with phone network systems, so that they become more accessible to people who stammer.

Dr Nola Chambers, of the University of Witwatersrand, Johannesburg, who concluded an evaluation of TAD in South Africa using different methods, has submitted a paper to the *South African Journal of Communication Disorders* entitled 'Impact of the Telephone Assistive Device (TAD) on stuttering severity while speaking on the telephone'.

<http://www.informaworld.com/smpp/content~db=all~content=a907770321>
www.voiceamp.net

Child Benefit

New Equipment for Suffolk

To support early intervention treatment for children who stammer, video cameras and laptops (which were not provided by the NHS) were purchased by the Trust at a cost of £14,500 for use in 13 Clinics in East and West Suffolk.

Peta Cook, Paediatric Speech and Language Therapy Manager for Suffolk Community Healthcare, said, "It will make a real difference to how we can provide vital speech therapy for children across Suffolk. The treatment we'll be using it for is highly effective in improving speech among children and benefits those children and their families hugely."

The cameras and laptops were introduced in Autumn 2008 and are already having a positive impact on the services and practice of SLTs. Isobel Pickering



who has undertaken research projects for the Trust, commented, "In the past therapy was often the sole domain of the specialist therapists. Now the families can have some input at their local clinic. The laptops enable the therapists to give live feedback so that the parents can see how they are getting on."

"The cameras are an invaluable resource with older children who often don't attend with their families, as they allow us to provide instant impartial feedback to the client. They can see for themselves how they are progressing in

therapy and achieve a realistic idea of how they are communicating without relying on the therapist telling them. Frequently the child in therapy believes that all communication is affected by dysfluency and feels very negative about talking. The video playback often offers the child some positive feedback when speaking fluently and this is sometimes a pleasant surprise to the child."

Equipment and training was provided by Jerry Walker of Domestic Computer Services

AMONGST DREAMING SPIRES

The 8th Oxford Dysfluency Conference

The Trust was well represented at the eighth international Oxford Dysfluency Conference held from 3rd-6th July at St. Catherine's College. The Conference takes place every three years providing an ideal opportunity to meet with people from all over the world who share an interest in Dysfluency.

Tammy Davidson Thompson, UEA, gave a presentation entitled 'Is current speech and language therapy practice meeting the psychological needs of adults who stutter?'

Dr Monica Bray and Dr Sarah James, of Leeds Metropolitan University, presented 'An investigation into the effectiveness of a telephone device (TAD) for people who stammer'.

Dr Per Alm, Uppsala University, gave two presentations: 'Fluency disorders: a discussion of possible causes and mechanisms, from a neuroscience perspective' and 'Stuttering and temperament, a review'.

Sarah Costelloe, the Research Associate at UCS also attended the conference.

All of these researchers were funded by, or supported by, grants from the Dominic Barker Trust.

Exchange of ideas

Dr Steve Davis OBE speaks at UCS Study Day



A Study Day held in March 2009 at the UCS was attended by 24 SLT's and other health professionals as well as three trustees.

Sarah Costelloe, Research Associate at UCS, made a presentation about early childhood dysfluency. She summarised some of the well-known research findings and talked about the existing projects at UCS, funded by Dom's Fund (see page 2).

Dr Steve Davis, OBE, (pictured above) of University College, London – who was awarded his OBE in the 2009 New Year Honours list, for his services to children with communication disorders – then presented some of their findings from UCL with older children. Therapists were interested in their new model which shows how you can predict recovery and persistence at 12 years.

In the afternoon there were two workshops – one discussing evidence-based practice, and the other about recognising and supporting pre-school children who stammer – one of which was delivered by Peta Cook, Paediatric Speech and Language Therapy Manager for Suffolk PCT.

Walking the Orwell walk

The Trust would like to thank Dorothy Kennerley who recently retired as Executive Dean, Faculty of Health, UCS. Dorothy has been supportive of the research funded by the Trust for many years both at Suffolk College and UCS.

The Trust's supporters continue to impress us with their many and varied efforts to raise money for Dom's Fund.

Originally planned for June 2008, The Orwell Walk was cancelled due to torrential rain and eventually took place the following September. Despite the later than planned start, and fewer walkers due to organisational changes, an impressive £2,000 was raised for the Fund by the walkers and their generous supporters. Amongst the walkers were former Trust Chairman Sir Malcolm Pill and Lady Pill seen here striding out.

Trustee Ian Angus and his wife Margaret did their bit for the walkers by organising a splendid lunch while fellow trustee Gill Garnham walked three times around Alton Water clocking up an equivalent 25 miles and raising over £1,200.

T shirts worn by the Orwell walkers and those undertaking similar fund raising events were kindly donated by Danes Laundry.

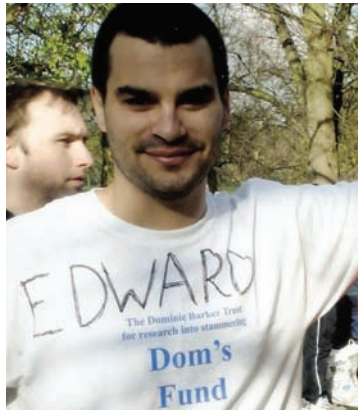
Sir Malcom and Lady Pill striding out



photo courtesy of the East Anglian Daily Times

GOING THE DISTANCE

Our special thanks go to Ed Cima who tackled the streets of London for a second time running the London Marathon in Spring 2008 and raising further cash for the Fund. Also to Paul Cann who ran the Bristol Half Marathon in September 2008 and to Eddie Gower Isaac who completed the Half Marathon up the side of Mont Blanc in September 2008. All sterling efforts on behalf of the Fund.



Left to right: Ed Cima, Paul Cann, Eddie Gower Isaac

THE FACES BEHIND THE TRUST



Toby Kramers, Chairman



Ian Angus



Eleanor Barker



Guy Barker



Christopher Brown



Chloe Chancellor



Gill Garnham

Would you like to help?

If you would like to make a donation, please complete this form and send it to: Dom's Fund, Pound Close, Holbrook, Ipswich IP9 2RA.

I enclose a donation of £
(Please make cheques payable to Dom's Fund)
Regard this as a Gift Aid donation Yes / No

(You must pay income tax at least equal to the amount we reclaim on your donation.)

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ABOUT DOM'S FUND



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THE DOMINIC BARKER TRUST, a charity known as Dom's Fund, was set up in 1997 in memory of Dominic Barker, who had a persistent stammer and who took his own life in 1994, aged 26.

The primary aim of Dom's Fund is to fund research into stammering, with a view to development of effective support for people who stammer and their families.

Dom's Fund is:

- Established, having funded 11 years' relevant research, with practical outcomes.
- Supporting local, and internationally relevant, research and practice in stammering.
- Working in partnership with researchers and practitioners to enable sharing of good practice and training.
- Developing a centre of excellence in East Anglia, integrating original research with the delivery of quality training and therapy.

To date, research and projects which Dom's Fund has supported include:

- Funding four published research topics at Suffolk College.
- A Research Fellowship at UEA, looking at developing best practice in therapy for adults who stammer.
- Study Days to disseminate research to Speech and Language Therapists: three held at Suffolk College and the most recent at UCS.
- Funding for practical equipment to support the work of Speech and Language Therapists in East Anglia.
- Funding for the evaluation of a Telephone Assisted Device to enable people who stammer to use the telephone more effectively.

Ongoing and upcoming projects include:

- Funding of a Research Associate at UCS, to identify those factors which may influence children to develop long-term dysfluency.
- Start/Stop project: evaluation of a practical play pack to support parent-child interaction therapy.
- Plans to fund a research project 'Empowering Children's Centres to recognise and support children who stammer' which aims to fulfil recommendations of the *Bercow Review* that "speech, language and communication should be prioritised by all Children's Centres and that it is a primary focus for measuring every child's progress".

HOW TO SUPPORT US

The Trust is entirely dependent on the generosity of its contributors.

To make a donation, please use the slip on page 5, or alternatively, visit www.dominicbarkertrust.org.uk or www.justgiving.com

Please support us by using the Dom's Fund Christmas Card

For further information, please visit our website www.dominicbarkertrust.org.uk or phone 01473 328530 or email domsfund.b@ukonline.co.uk

WHO WE WORK WITH

In association with:



BRITISH STAMMERING ASSOCIATION (BSA): www.stammering.org
15 Old Ford Road, London E2 9PJ Tel: 020 8983 1003 Helpline: 0845 603 2001
The BSA works on behalf of people who stammer of all ages and their families, providing a free information service on all aspects of stammering and stammering therapy, and also co-ordinates a programme of events.

ICVS: the Ipswich Council for Voluntary Service

SAVO: Suffolk Association of Voluntary Organisations.

The Trustees are grateful to: Beverley Wigg for editing this newsletter (www.beverleywiggpr.co.uk); Technographic Design and Print for its production (www.technographicdesign.co.uk) and Ashton Graham, Solicitors, of Ipswich and Bury St Edmunds for funding its distribution (www.ashtongraham.co.uk)