

# Dom's Fund

## Figures of speech

Tammy Davidson Thompson is well known in the dysfluency community, so it comes as no surprise that her work has been recognised with the prestigious Travers Reid prize 2011, presented at the Michael Palin Centre for a research project on stammering. Tammy's PhD research – at the University of East Anglia (UEA) - focused on the way that British Speech and Language Therapists (SLTs) help clients deal with the psycho-social impact of stammering.



*Dr Tammy Davidson Thompson with her award*



*Michael Palin at the award ceremony*

Commenting, Dr Jan McAllister, Senior Lecturer at UEA, who collected the award on Tammy's behalf, said: "Tammy's research recommended that NHS funding would be best targeted on funding specialist therapy sessions." Tammy has made presentations at several conferences and published in the International Journal of Speech-Language Pathology. Furthermore, her findings were cited in a research synthesis produced by the Royal College of Speech and Language Therapists – which summarised good practice for working with people who stammer.

Congratulations go to Professor Penny Cavenagh who has been awarded an Essex Chair in Health and Enterprise at University Campus Suffolk (UCS). Penny's long and valued association with the Trust and support for people who stammer is much appreciated and we are delighted to hear of this latest milestone in her distinguished career.



## Home and away

The Trust's mission is to support research into stammering and while the important Longitudinal Study and StarTalking project continue we are also delighted to update you on a number of new projects.

The Longitudinal research has led to a new study investigating the attitudes towards speech therapy of the parents of young people who stammer. This is vital research if families are to get behind the therapy their children so desperately need.

For the first time, stammering in the workplace has been the focus, with a new project undertaken by Newcastle Business School. The research concentrated on the employment experiences of people who stammer – work that has provided important insight and which we feel will lead to a greater understanding of the obstacles that have to be overcome in the workplace.

In collaboration with University College London (UCL) we have also embarked on new research entitled 'Screening school-aged children for risk of stuttering and other communication disorders'. This is a PhD research project, which will deal with the need for early detection.

Read on to find out more about all the research funded by the Trust – existing and new.

## View from the Chair



Since our last newsletter a great deal has happened. Our research continues to yield valuable information, which will eventually help children and adults who stammer to manage challenges in the home, school and in the workplace.

In this issue we update you on these projects, celebrate the achievements of some of our greatest supporters and recognise the continuing efforts of individuals, companies and organisations who tirelessly raise money. We say this again and again, but we simply could not fund this good work without your generosity, time and spirit. Thank you for your continued support!

**Toby Kramers, Chairman**

# Working wonders

## Stammering in the workplace

The Trust funded a research project entitled 'Stammering and the Workplace' conducted by Dr Clare Butler from Newcastle University. She used qualitative research to elicit stories of the employment experiences of people who stammer (PWS).

The results were well received by the British Stammering Association (BSA) National Conference in Lincoln and the British Academy of Management (BAM) conference at Cardiff University, with the latter being particularly important in raising awareness amongst employers.

Three main themes emerged. First, the initial job interview often presented a major challenge to PWS. Participants felt they were not respected for what they had to say and this was most evident, and of greatest importance, during recruitment.

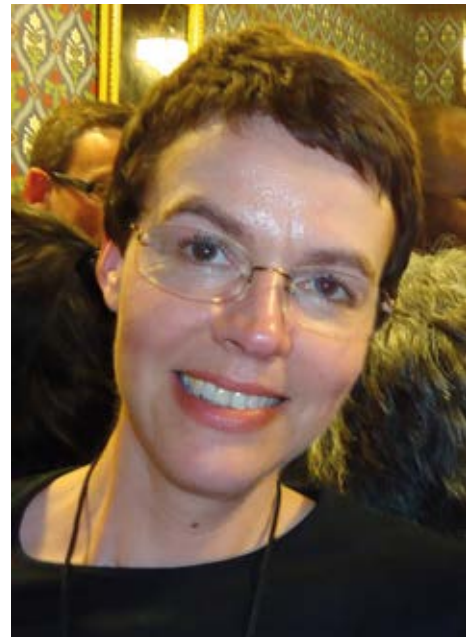
Second, participants described their experiences of discrimination by others during recruitment and at work generally, but there was also evidence of self-discrimination, with many avoiding certain careers or roles because of their speech. A number sought low profile jobs or preferred lone working, limiting their own career aspirations.

Finally, a number of participants

discussed the changing work context and a reduction in the roles that are, or would be, available to them as PWS. They often felt excluded from the rapidly growing service or retail sectors, which involved immediate speech encounters and were described as challenging, difficult or impossible for PWS to perform.

However, it was not all negative. Participants engaging in on-going relationships with customers, partner organisations or colleagues, used their enhanced listening skills to great effect, attributing their heightened empathy and ability to connect with others to being a PWS – and adding value to their role. Participants who achieved an alignment between stammering and the workplace talked openly about their stammer highlighting both the difficulties they faced and the strengths it gave them. They had seemingly altered the significance and classification of being a PWS - moving their stammer from being representative of difference to being representative of similarity.

Summing up Dr Clare Butler said: "I would like to thank both the participants and the Trust. I hope this project has helped to move the conversation of



*Dr Clare Butler*

stammering into places and spaces that have until now been silent."  
clare.butler@newcastle.ac.uk

## New Corporate Stammering Network

The Trustees welcomed the invitation to attend the launch at the House of Commons of the Corporate Stammering Network initiated by the BSA and by Iain Wilkie, senior partner of the management team at Ernst & Young LLP who writes: "The Network's aim is to help employers create a culture where people who stammer can achieve their full career potential."  
nl@stammering.org

# Screen test

## Project in schools

The 2008 Bercow Review of the speech, language and communications needs of children and young people emphasised the need for early detection and intervention of communication disorders. A screen that could be performed on children at school intake would be one way of achieving these goals. All children could be examined and those with communication difficulties separated off for assessment and possible intervention.



*Professor Peter Howell, UCL*



*Avin Mirawdeli with one of her young participants*

Avin Mirawdeli, supervised by Professor Peter Howell of UCL, has started to investigate how this can be delivered, through a three year PhD research project funded jointly by the Trust and UCL.

A pilot test with 600 children per year from the reception classes of ten schools in London has so far been undertaken. Work will continue over the next three years with the opportunity to include children from Suffolk Schools.

a.mirawdeli@ucl.ac.uk and p.howell@ucl.ac.uk



# Coming a long way

## Early childhood stuttering

The majority of families taking part in the UCS Longitudinal study on early childhood dysfluency – conducted by Sarah Costelloe, Dr Steve Davis (OBE) and Professor Penny Cavenagh – have completed two years in the study, with some participating for three or four years. Many children have now recovered with only 10 of the initial 43 still stuttering.



*A child takes part in the Attention Study*

Initial analysis to identify the key risk factors for persistence of stuttering suggests the main factors putting

children at risk of a long term stutter are: the severity of stuttering, a family history of the disorder, gender and left handedness.

Further analysis is required but it appears that the therapy children have received has not necessarily increased their chances of recovery, but less than half of the children received regular therapy. These results could have significant clinical implications. Speech and Language Therapists can readily collect these details at the initial assessment to identify a child's risk for long term stuttering, and then focus on those whose chance of spontaneous recovery is lower.

The study has identified other potential factors that may be linked to stuttering. One of these is attention control in children, with the hypothesis that children who stammer have weaker attention control than those who don't.

Measuring attention is difficult in young children, but a standardised assessment (Test of Everyday Attention for Children or TEA-Ch) on the



*Sarah Costelloe in Tours*

children who stammer and the control group may reveal if there are any differences in attention/concentration. The test can only be carried out on children of six years or over but there should be sufficient data to analyse in a few months' time.

This research was presented at The IFA World Congress on Fluency Disorders in Tours, France, July 2012, The BSA Cambridge Open Day, March 2013 and The Eastern Region Dysfluency SIG, held at UCS, April 2013.

s.costelloe@ucs.ac.uk

# Family matters

## Parental attitudes to stammering and therapy

The UCS team is also embarking on new research, which builds on the Longitudinal study and capitalises on the strong relationships which have been forged with families over recent years.

The questionnaire-based study, the first of its kind in the UK, aims to reveal what parents think about the causes of their child's stammer, the coping strategies they use and their experiences of therapy. This study, in conjunction with the BSA, should be completed by the end of the year.

The current study revealed that there were significant differences between the families of children who stammer

(CWS) and children who do not (CWNS). The health, behaviour and attention and learning difficulties of CSW caused parents more concern compared to parents of CWNS. They also reported greater difficulties in getting along as a family – findings supported by Beilby (2012).<sup>1</sup>

These differences may be as a result of the stammering or another causative factor. Further investigation by a researcher who is not generally the child's SLT aims to reveal honest insight into these differences and into parents' attitudes toward speech therapy. For example, some have not wanted therapy, or been satisfied with

it and some parents believed that it was started too young – which conflicts with the current drive on early intervention. Parents, with a child under 10 who stammers, are welcome to take part in the survey. It will take about 15 minutes and involves canvassing parents' views on their child's stammer and any therapy they may have had. Contact Sarah for details.

s.costelloe@ucs.ac.uk



*Sarah Costelloe interviews a parent*

<sup>1</sup> Lau S., Beilby J., Byrnes, M. and Hennessey N (2012) Parenting styles and attachment in school age children who stutter. *Journal communication disorders* 45, 2 98-110

# The home straight

## StarTalking project

The 'StarTalking' project, conducted by Isobel Pickering (Highly Specialist SLT) and assisted by Rachel Pennick, evaluated the effectiveness of an activity box for parents to use at home with very young children, often while waiting for speech therapy to become available. The play-based activities were lent to 16 Suffolk families for a period of around three months, supported by phone calls and visits



Rachel Pennick

from the research team. Parents kept track of the children's progress using a speech rating system.

Feedback, obtained from 11 parents and largely positive, included:

"Her speech has been so smooth for so long; I've forgotten about it."

"It helped me to learn to cope... we didn't know what to do."

"It was the most supportive medical intervention I have

ever experienced for my child."

Analysis of the speech data from 12 families indicated that the therapy had 'value' and was appreciated as a method of creating fluency. None of the children's

fluency worsened and the majority saw improvements. Due to the relatively small-scale nature of the project, it is not possible to say that this therapy 'works' as it has not been compared with other studies – or with placebo. However the research has indicated how this type of approach could, after more rigorous testing and some improvements to equipment and method of delivery, offer an alternative to the more traditional type of clinic-based therapy for some families.



Isobel Pickering

isobel.pickering@suffolkch.nhs.uk

# Dressing down



Chairman Toby Kramers receiving a cheque from Alison at Willis Ltd.

One child to benefit from the StarTalking project was Sam Connolly-Barker. His mother Alison commented: "The programme really helped Sam in his speech and both my husband and I were delighted with the results and the support we had from Rachel Pennick and Isobel Pickering." By way of a 'thank you' Alison nominated Dom's Fund for a charity dress down day at Willis Ltd in Ipswich last September and this, along with a prize draw and cake stall, raised a sizeable and welcome sum.



Sam Connolly-Barker takes time out

# Emotional intelligence

Louise Helliker has been using a system called Semantria, which performs sentiment analysis of samples of speech transcriptions collected during the Longitudinal study. Sentiment analysis aims to determine

the attitude of a speaker or writer – such as his or her judgement or evaluation, emotional state, or the emotional effect the author/speaker wishes to have on the reader/listener. The results are being incorporated into a report for Sarah Costelloe.



Louise Helliker

It is hoped that this type of analysis will reveal factors about the linguistic development of children who stammer, which

may be different from other children of the same age. For example, they might have smaller or larger vocabularies, express their emotions less or more, use a wider or narrower range of bi-grams (word pairs) or have different levels of self-awareness – all information which may be useful for teachers or therapists.

This work has been made possible thanks to British Telecom's (BT's) volunteering programme which actively supports employees' efforts to get involved in their local communities. louise.helliker@btinternet.com



# Open house in Cambridge

Professor Penny Cavenagh, Dr Steve Davis and Sarah Costelloe had the opportunity to present details of the UCS Longitudinal Study and their initial findings at the BSA Open Day in Cambridge in March this year. The purpose of the research project is to identify the factors that lead to long-term stammering and using the theme 'Who will recover?' the team discussed the possible reasons why some children recover and others do not. Establishing the reasons behind this are key in developing our understanding of what stammering is and what can be done to target those children most at risk of a lifelong stammer.



*Dr Steve Davis, Sarah Costelloe (centre) and Professor Penny Cavenagh at Cambridge*

# Seeking evidence in Norwich



*Dr Jan McAllister*

On 2nd March this year, the Trust funded a study day for SLTs at UEA focusing on 'Stammering and Psychosocial Issues'. Welcoming delegates, The BSA's Norbert Lieckfeldt emphasised the importance of establishing an evidence base around this significant aspect of stammering.

Views were given from a number of perspectives:

Dr Jo Hodgekins (UEA) gave a clinical psychologist's perspective; Dr Tammy Davidson Thompson (Norwich Community Health & Care) talked about her survey of SLTs who work with adults who stammer, funded by the Trust and Ali Berquez (Michael Palin Centre) spoke about bullying and stammering.

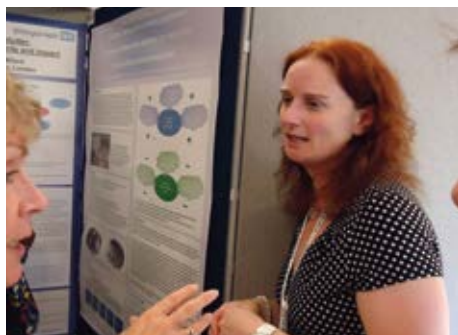
Dr Jan McAllister, who organised the event along with her colleague Sally Gascoine, described the research into stammering and psychosocial issues taking place at UEA. See [www.dominicbarker.trust.org.uk](http://www.dominicbarker.trust.org.uk) or email [MOSAICS@uea.ac.uk](mailto:MOSAICS@uea.ac.uk) for further information.

Feedback on the event was extremely positive, with delegates benefiting from both the presentations and the opportunity to interact with other professionals who work in this area.



*Delegates at the UEA Study Day*

# Bridging the gap in Oxford



*Isobel Pickering at Oxford*

Research funded by the Trust was well represented at the 9th Oxford Dysfluency Conference, which took place in September 2011, just as our last newsletter went to print. The conference is one of the leading international scientific conferences in the field of dysfluency bringing together researchers and clinicians - and it provides a showcase and forum for discussion and debate about the most current and innovative research and clinical practices. Throughout the history of ODC, the primary aim has been to bridge the gap between research and clinical practice; to promote research that informs management, with interventions that are supported by sound theory and which inform future research.

It is therefore highly satisfying to see such a strong presence for the Trust with

Sarah Costelloe and Dr Steve Davis, accompanied by Professor Penny Cavenagh, presenting initial findings of the Longitudinal study and Dr Tammy Davidson Thompson and Isobel Pickering each discussing their work, which was portrayed by posters, with delegates.

[tamara.davidson@nchc.nhs.uk](mailto:tamara.davidson@nchc.nhs.uk)

*Right: Dr Tammy Davidson Thompson at Oxford*



# Magic touch

The Merlin School – a pre-prep school for boys and girls aged four to eight, in the heart of Putney – worked its magic by raising money for the Fund. Kate Prest, the School Head at Merlin, explained that their practical approach to education includes raising money for good causes – something they feel is every bit as important to a child’s education as class based learning. A school ‘mufti’ day on the last day of term and a fabulous ‘café’ run by parent representatives Wendy Howard and Theresa Ashurst at the Olympic Day were amongst the initiatives that led to a substantial cheque for the fund.



Some of the children of The Merlin School



Felix and Inigo get on their bikes

# Le Tour de Shotley

Felix Sheppard and Inigo Chancellor (12 and 13 years old respectively at the time) completed an impressive 25 mile bike ride on the Shotley peninsula on 9th September last year, in aid of Dom's Fund. Beginning in Erwarton, they cycled towards Shotley Church, up through Chelmondiston then over to Alton Water. After cycling around the reservoir, they headed home via Lower Holbrook and Harkstead. The pair felt a great sense of achievement and are planning another fundraising adventure in due course.

# School's out

The prestigious Royal Hospital School has been a regular supporter of the Trust's work – this time nominating the Fund as one of the beneficiaries from their concert in March 2012.



# Roll Call

We would also like to thank the very many individuals and organisations, some of whom know first hand the impact stammering can have on peoples' lives, for their generous donations and support over the years. Recent supporters include:

Altorian Chartered Accountants - Big Six Design - Bill Fone Pollitzer Charity - Dr Tim Andrews legacy - Farrer Brown Trust - Harkstead Community Council - Holbrook Gardens Angling Club - Holbrook Gardens Shooters - Holbrook Methodist Church - Holbrook Parish Council - Inner Wheel District Committee - Keith Walkerdine's Legacy - Magdalen School Oxford - Merlin School - Orwell Park School - RJV Cadbury Charitable Trust - Royal Hospital School - Sir James Reckitt Trust - Sir Robert Gooch Trust - St Andrews Church Chelmondiston - Suffolk Life Charitable Foundation - Suffolk Lones - Suffolk Provincial Grand Charity - Suffolk Trefoil Guild - The Rotary International Conference 2011 - Willis Charity.

# A run for his money

David Merrick shed his business suit – he is Head of Development at Savills, the international property consultants in Norwich – to join over 36,000 runners in the Virgin London Marathon last year. With a time of 4 hours and 41 minutes, he was only one minute behind his target time – a great result - and a generous donation to the Fund.

David decided to go for his first full marathon this time (after a couple of half marathons) and the lanes around his South Norfolk home were his training ground.



David Merrick at the start of the London Marathon



# PICTURE THIS...the Trust's new greetings card

We have talented photographer John Lowe to thank for our winter inspired double-sided Christmas card this year. The front features the River Delph, to the south of Welney in the Fens. The back shows a mixed flock of Whooper and Bewick swans – stunning in flight.

John was accompanying his brother, David, who has a great deal of experience of ice-skating. His ability to venture out onto the frozen river and into the heart of nature has led to these atmospheric photos. It should be said that years of experience, including skating on the sea in Sweden, and the right safety equipment, meant they could do this in comparative safety. It isn't to be recommended to amateurs!

The cards – either with a Christmas message or blank for your own – can be ordered by post or online with a donation of £5 for ten. And if you would like to find out more about ice-skating, David Lowe has a fascinating story to tell about how he got into the sport, his efforts to promote ice-skating and the best places to skate today. Visit [www.dominicbarkertrust.org.uk](http://www.dominicbarkertrust.org.uk) and follow the link to our 2013 Christmas cards to read his story and find out how you can buy these cards.



## THE FACES BEHIND THE TRUST

Our thanks and best wishes go to Gill Garnham who is retiring from the Trust after six years of unfaltering support and we warmly welcome Dr Sally Williams – a retired GP.



**Toby Kramers,**  
Chairman



**Ian Angus**



**Eleanor  
Barker**



**Guy Barker**



**Dr Christopher  
Brown**



**Chloe  
Chancellor**



**Dr Sally  
Williams**

The Trustees are grateful to:

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## ABOUT DOM'S FUND



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 16 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, integrating original research with the delivery of quality training and therapy.

### THE DOMINIC BARKER TRUST

Hon DCL (East Anglia)

Registered Charity No 1063491

Pound Close, Harkstead Road, Holbrook, Ipswich IP9 2RA

Tel 01473 328530

enquiries@dominicbarkertrust.org.uk    www.dominicbarkertrust.org.uk

## WORKING WITH

BRITISH STAMMERING ASSOCIATION (BSA): [www.stammering.org](http://www.stammering.org)  
15 Old Ford Road, London E2 9PJ Tel: 020 8983 1003 Helpline: 0845 603 2001  
The BSA works on behalf of stammerers 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.

COMMUNITY ACTION SUFFOLK

[www.communityactionsuffolk.org.uk](http://www.communityactionsuffolk.org.uk)

## IN ASSOCIATION WITH



## HOW TO SUPPORT US

**The trust is entirely dependent on the generosity of its contributors.**

You can make a donation:

ONLINE:            At [www.dominicbarkertrust.org.uk](http://www.dominicbarkertrust.org.uk)  
                          where you will be redirected to the Just Giving site.

BY POST:            Send a cheque using the slip below.

For further information about the Trust and to discuss ways you might help please visit the website or contact us:

BY PHONE:        01473 328530

BY EMAIL:        enquiries@dominicbarkertrust.org.uk

**Your donations are used only to fund research and activities related to research projects. The Trust has minimal overheads; it has no employees, owns no property or vehicles and the administration is done freely by trustees and volunteers.**

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you like  
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Dom's Fund

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