

Dom's Fund

BREAKING DOWN BARRIERS

The British Stammering Association's (BSA's) Employers Stammering Network (ESN) - which originated from a study carried out by Dr Clare Butler and funded by the Dominic Barker Trust (DBT) - has gone from strength to strength.

Last year saw the appointment of Helen Carpenter as network manager of ESN. Not only is she highly experienced but she has been a positive catalyst for ESN, which continues to secure new members, most significantly the Civil Service, which joined in October 2015.

The ESN has run a series of three Redefining Stammering at Work workshops with stammering champions from a number of employers. Run jointly by specialist speech and language therapists (SLTs) and with EY's Iain Wilkie contributing his business expertise, these have been very successful in enabling participants to address the issues they face at work.

In addition, the ESN has recently held its first workshop called Introduction to Stammering for HR staff and line managers of people who stammer (PWS), offering concrete strategies and examples of workplace adjustments which benefit not merely people who stammer but all employees. The ESN constantly draws on the rich findings of the aforementioned study, carried out by Clare Butler in 2014 at Newcastle University, which provided much-needed insight and greater understanding of the obstacles that need to be overcome in the workplace.

The work of the ESN has clearly made a difference, most obviously at a personal level. One of the ESN's Defence Stammering Network champions has been promoted to officer rank in the Army and his work for the ESN was recognised with an MBE in this year's Honour's List. Another has just recently won an internal People's Oscar award in his company for his work raising awareness of stammering. People have had the courage to move on to other employers and have put themselves forward for promotion when, just one year ago, they would not have done so.



Iain Wilkie with Sam Simpson (centre) and Rachel Everard

The network also works on a strategic level, with Co-Chair Norbert Lieckfeldt now representing the ESN on the Experts Advisory Panel of the Civil Service's Disability Champion. In future, the aim is to widen the scope from employment to employability, supporting those who struggle to find work as well as those who are setting out on their career.

Note: Norbert Lieckfeldt and Iain Wilkie talked about the work of the ESN at a Trust Open Evening at UCS (now University of Suffolk) in October 2014.

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Rachel Everard at the Stammering Awareness for Managers Course

A word from the Chair

Welcome to this year's newsletter from Dominic Barker Trust.

The Dominic Barker Trust continues to fund and support research into the causes and treatment of stammering. In this edition, you will read about research into the relationship between stammering and attention deficit issues, the treatment of stammering in the workplace and the use of electronic stimulation to the brain as a form of treatment along with other initiatives.

None of this work would be possible without the continued support from individuals, trusts and organisations, which have made donations and have organised fund raising events on behalf of the Trust.

We are enormously grateful for your continued support and I do hope that you will find the newsletter interesting and stimulating.



Toby Kramers

ROUND ROBIN



Robins have long epitomised Christmas. Find out why and view The Trust's 2016 Christmas cards on page 5.

THE BRAIN GAME

Brain imaging research into stammering and speech mechanisms

Thanks to a very generous donation from the Mackie Foundation, the Trust is delighted to be co-financing a PhD with UCL, which is investigating the Impact of Transcranial Direct Current Stimulation (tDCS) on Speech Fluency. Researcher Naheem Bashir, supervised by Professor Peter Howell, is investigating the effect of stimulating the brain with tDCS in conjunction with the use of conventional treatment for stammering.

He has so far shown that this combination does seem to work to improve speech in fluent speakers, so providing proof of the principle that tDCS can have a positive effect on speech mechanisms.

Naheem is following several lines of research. One study involves tDCS as an adjunct to conventional therapy. Another study currently being planned aims to assess if tDCS is more effective when delivered during or before an assessment.

A further study will involve using a brain imaging system (NIRS) to look at assessing brain activity in real-time in social situations, as well as fluency enhancing situations, in people who stammer.

Naheem hopes this will give an insight into the mechanisms of stuttering, as well as fluent speech production in people who stutter, and an insight into variations in speech fluency levels experienced by people who stutter in various different situations; for example high fluency when speaking alone as compared to low fluency when introducing oneself to a stranger. This could possibly provide new neural targets for treatment and have exciting implications for use in therapy.



Naheem Bashir



One of the participants in the tDCS therapy

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Exchanging Words

The work of speech and language therapists

Dr Clare Butler of Newcastle University is researching the work of SLTs. The aim is to gain greater understanding of working as a SLT and of the impact of a changing context, including the effect of external pressures within the healthcare sphere.

Following her review of current knowledge in the area, Clare interviewed 33 SLTs from around the UK. Analysis of the interviews, which is ongoing, is being considered in light of prior studies in work and employment literature.

At the time of going to print, Clare will be presenting her embryonic ideas at the British Sociological Association, Work, Employment and Society conference at the University of Leeds (September 2016). Attendance at the conference and, more specifically, discussions with the audience at the 'Professions, occupations, skills and social mobility' stream, will be invaluable in strengthening Clare's ideas.

With the support of the DBT, this research project hopes to make a contribution not only to the academic debates, but also to policy and practice in the field of speech and language therapy.



Dr Clare Butler

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A call to Attention

Research on attention and stammering in adults

Researcher Silviya Doneva has recently completed a year-long research project investigating the links between attention and stammering in adults, funded by the Trust and supervised by Professor Penny Cavenagh at University Campus Suffolk. This builds on earlier work undertaken at UCS, which found that children who stammer may also experience difficulties with sustaining attention.

Silviya has been testing the hypothesis that stammering interferes with control of processing information and thereby affects the performance of everyday tasks. She has found a difference in attention between people who stammer and people who are fluent speakers and that people who stammer have more difficulty in sustaining attention when undertaking tasks. Although her research suggests a link between the severity of a stammer and difficulties with attention, it is not clear which is cause and which is effect.



Dr Silviya Doneva

The project, which was carried out at both UCS and UCL, to ensure the population was fairly represented, was completed in May 2016 and submitted to a high-impact academic journal on fluency disorders. The findings have been presented at the 30th World Conference of the International Association of Logopedics and Phoniatrics (August 2016) and sparked local interest.

The team expressed their thanks to City Lit's Rachel Everard, BSA's Norbert Lieckfeldt and Allan Tyrer - for raising awareness and aiding recruitment - and Professor Peter Howell for providing a testing venue in London; also to the Trust and all the participants.



Professor Penny Cavenagh

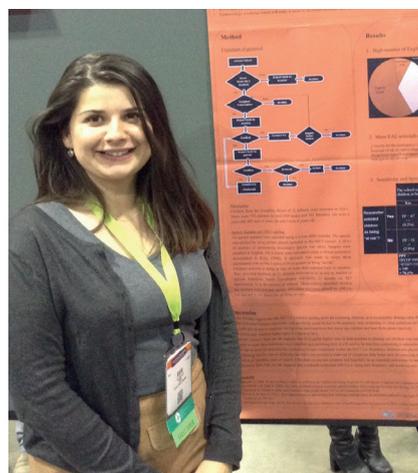


Professor Peter Howell



Dr Steve Davis OBE

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Avin Mirawdeli at work

School of thought

Screening school-aged children for stammering

Avin Mirawdeli, supervised by Professor Peter Howell of UCL, has completed her PhD project at UCL, which is co-funded by the DBT and UCL. Entitled "Screening school-aged children for fluency problems: an investigation in Suffolk Schools", Avin has been working to develop a universally-applicable screening tool to identify children in reception class who have speech difficulties.

Her work has received positive reactions from the schools where she undertook her research. The work identifies children in schools who stutter (in Ipswich and London) and following identification, schools have also asked that in-school interventions be conducted for children who either: 1) stutter or 2) show word-finding difficulty that can sometimes sound like stuttering. The latter affects children who do not speak English as their native language in schools.

Four papers are at different points in the publications process. Further details can be found at <https://www.ucl.ac.uk/speech-research-group/projects/screening-children-for-speech-difficulties>

Building on Avin's work, researchers at UCL, funded by the Trust, are developing an intervention for in-school use with children who stutter. This study first validated Avin's procedure by applying the screen on 170 reception class children. The effectiveness of the newly-designed two-week working memory intervention was investigated, testing the hypothesis that working memory training would lead to short- and long-term improvements in speech fluency and non-word repetition (NWR) ability. As predicted, results showed immediate improvements and long-term retention in effects for both speech fluency and NWR ability. Schools now have a package that allows them to identify and perform a preliminary intervention for speech difficulties among reception class children.

This project stemmed from recommendations in the Bercow Report that had emphasised the need for identification and intervention by teachers and SLTs; coordination of services between schools and clinics, and equity of access.

"I'd like to thank the DBT, its supporters and participating families." Said Professor Howell, who as this newsletter goes to print, will be giving a keynote presentation about this work at the annual meeting of the British Stammering Association in September 2016.

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Autumn 2016

Lost in space!

The Star Talking project

The Star Talking Project, which started in 2009, focused initially on providing a box of resources to parents of very young children (under five) who stammer, in order to encourage more fluent talking at home. Conducted by Isobel Pickering, a highly specialist SLT working in Suffolk, it was designed to create something practical, fun and helpful to do with children during the early stages of stammering, where there is often a waiting list for therapy.



Isobel Pickering

The Star Talking Boxes were well liked by most families and children and in those cases were successful in promoting fluency in the children. However, for some participants the resources were not always suitable.

Following completion of the first stage of the project, it was decided to develop a book that embedded some of the principles of therapy that a child might receive in a clinic-based situation. Written by Isobel and edited by local SLT Harriet Ziegler – it features a

space girl who is lost. On each page the child needs to do some talking, with the help of an adult, to win sticker stars and help the girl find her way home.

"I am now in the exciting position of having 15 copies of the book ready to trial amongst families of very young children who stammer." Says Isobel who expects the book to provide a useful, practical and convenient method to encourage fluent speech.



Use of the book will be overseen by local SLTs and it is intended to add to, rather than replace, the range of interventions currently offered. Its value will be piloted before it can be rolled out.



Isobel expressed her thanks to the DBT, also to Robert Pymar at Red Bird

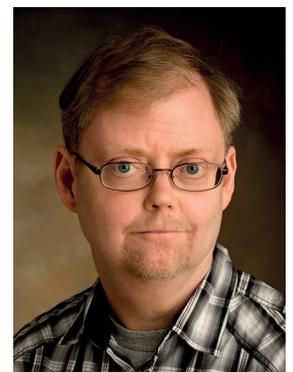
Publishing, for printing the book and to illustrator Daniel Brown. The trustees are grateful for donations from the Grimwade Trust, the Tanyard Trust and the Suffolk Foundation and many others, which enabled DBT to undertake this work.

Exploding the Myths

What is stuttering?

At Uppsala University, Department of Neuroscience, Dr Per Alm and his team believe there is still a lack of consensus regarding the type of disorder stuttering is and they are working towards a greater understanding of the basic nature of stuttering. This has led to an analysis of the moments of stuttering in detail at a 'micro level' to see what goes wrong in the speech process.

He explains: "A widespread assumption is that the speech disruption in stuttering is caused by excessive muscular tension. Although this is one of the most striking aspects of many cases of stuttering, it may only be one side of the coin. It is possible that failures to activate required speech muscles is another fundamental aspect of stuttering, which is easily overlooked because of the subtle symptoms. Brain research data seems to indicate that the core of stuttering is related to the speech motor system, or more specifically to the premotor system, which is crucial for the preparation of speech movements. Without proper preparation the speech movements may become unstable, and the intended smooth movements may either fail to start or become exaggerated and out of control."



Dr Per Alm

For a long time it has been assumed that excessive tension in stuttering is related to exaggerated emotions of anxiety or fear in social settings. However, there is now strong evidence that speech-related anxiety in persons who stutter typically is a result of the basic speech problem and not a primary cause of stuttering. For example, children who begin to stutter do not show higher levels of anxiety or shyness than other children, and emotionally reactive children do not appear to have higher risk for development of persistent stuttering. In fact, contrary to what might be expected, some data suggests that emotionally reactive preschool children may have somewhat better odds for recovery from stuttering than other children. It is possible that these indications are just random effects in the data, but it does highlight the importance of investigating stuttering without preconceptions about the causal relations. (These issues, and others, are discussed in a review article in *Journal of Fluency Disorders*, 2014, vol. 40 p. 5-21. The data on the speech motor analysis is under preparation for publication.)

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RESEARCH SUPPORTED BY THE TRUST

A LONG RUN

Improving the outcomes of children who stammer

Since 2008 Sarah Costelloe (UCS) has been responsible for some important work on stammering, in association with her colleague Dr Steve Davis (UCL) and under the guidance of Professor Penny Cavenagh.

Now living and working in Canada, Sarah leaves a legacy that will have a considerable impact on therapy in the future. Her work included a longitudinal study, which will help SLTs identify which young children are at greater risk from persistent stammering into adolescence and adulthood, and ensure scarce resources are targeted appropriately.

A second study sought to identify attention deficits in children who stammer and it was the first to use an objective, direct measure, rather than relying on more subjective parental reports. The results confirmed their hypothesis that children who stammer do have poorer sustained attention than children who do not, and that those who persist in stammering also have poorer attention than those who recover.

Sarah's most recent research – an on-line parent survey, in association with the BSA – revealed that parental concern is extremely high and explored how parents receive advice and assessed their attitudes to professionals and to speech therapy.



Sarah Costelloe

FUNDRAISING

WHERE THERE'S A WILL

The DBT has been fortunate to have so many supporters over the years. Amongst other things, they have walked, climbed, run and cycled to raise funds. The trustees also appreciate all the private donations that have quietly found their way to the trust. Increasingly, the DBT is benefiting from legacies and they are extremely grateful to a number of past supporters who have considered the trust in their wills.



Barry Searle - who asked guests for donations in lieu of presents at a significant birthday celebration

FUNDING FEAST

Suffolk New College's Shelley's Restaurant was the venue for a fund raising dinner in March 2014. The three-course meal was cooked and served with aplomb by students, whilst academic magician, Dr Todd Landman, provided fascinating entertainment. Thanks to all those who attended.

RED LETTER DAY

There are two schools of thought to explain the popularity of robins at Christmas. One tale goes back to the birth of Jesus. It was said that the robin helped to keep the fire in the stable going by flapping its wings. Another went back to the 1800s when British postmen, who were nicknamed 'robins' on account of their bright red uniforms, were the popular carriers of Christmas cards and an inspiration to artists.

Whatever the truth, they are a firm favourite and appear front and back on the Trust's cards this year. Measuring 15 cm x 10 cm and printed on quality card, they are available via the website www.dominicbarrkertrust.org.uk at £5 for 10. All proceeds go to the trust.



TRUSTEES NEWS

CHANGING FACES



Dr Chris Brown, one of the founding members of the trust, has retired after 19 years. A Cambridge graduate, he was a GP in Ipswich for over thirty years and knew Dom throughout his life. They shared a love of sailing and Dom joined his father and Chris in a shared Ajax from time to time. Chris has a deep understanding of the problems faced by people who stammer and his shrewd knowledge of medical research ensured the Trust's funds could be spent wisely. The Trust is deeply grateful to him.

The Trust is delighted to welcome Dr Steve Davis OBE. Following the award of his PhD (Factors in the identification and treatment of stuttering) in 2002, Steve has continued to investigate stuttering with research groups at UCL and UCS. In 2009 he was awarded an OBE for his work with children who stutter. Steve welcomed the opportunity to become a trustee and continue his work in this capacity and The Trust counts itself fortunate to have him on board.



WHAT IS 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 the development of effective support to people who stammer and their families.

The Dominic Barker Trust, Hon DCL (East Anglia), Registered Charity No 1063491, Pound Close, Harkstead Road, Holbrook, Ipswich IP9 2RA. 01473 328530 enquiries@dominicbarkertrust.org.uk www.dominicbarkertrust.org.uk

BOARD OF WISDOM

The work of the DBT would not be possible without a dedicated board of trustees who ensure the work is carried out responsibly and cost-effectively and that it meets the stated objectives and aims. The trustees – who come from different backgrounds and bring a wide range of skills and experience with them - also work tirelessly to support fundraising initiatives and to promote the cause.



Toby Kramers,
Chairman



Ian Angus



Eleanor Barker



Guy Barker



Dr Steve Davis
OBE



Chloe
Chancellor



Dr Sally
Williams

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Working with the
British Stammering Association



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 where you will be redirected to the Just Giving site.

BY PHONE: 01473 328530

BY EMAIL: enquiries@dominicbarkertrust.org.uk

BY POST: Send a cheque using the slip below.

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
to help?
Dom's Fund

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