

Dom's Fund

Who else is there?

By Norbert Lieckfeldt, Chief Executive of the British Stammering Association (BSA)

Who else is there for us? Stammering is such a serious communication disability. And yet it's a Cinderella subject, even more so for adults. There are 15,000 speech therapists in the UK but fewer than one per cent are members of the Dysfluency Clinical Excellence Network. I'd be surprised if we spend as much on stammering research in a generation in the UK as the US and Australia spend in one year.

This is why the Dominic Barker Trust (DBT) is such a wonderful, crucial, important and unique idea. Who else is there for us?

It was an idea born out of a family's tragedy. I was there, sitting in our office in London's Old Ford Road, when the very sad news broke. And the question was then, as the question must be, "Where did BSA fail?"

If you asked our members what they wanted BSA to do, most of them would say "Make sure no child goes through what I had to go through when I was that age." It's that same selfless instinct that turned tragedy into something amazing. The recent research on Stammering and Aesthetic Labour - by Dr Clare Butler, funded by the DBT, is a prime example of research that impacts directly on the BSA.

The examples of blatant discrimination, the 'emotional labour' that people who stammer expend to find their role in the workplace, the discrimination rooted in the subconscious "not sounding like us" by people who don't stammer, and most shockingly the internalised oppression of people who stammer - all this is flowing into what BSA does and how we tackle the issues around stammering at work.

Who else is there for us? In terms of research that makes a difference, the DBT has been here for people who stammer for almost 20 years. I hope it will be here for us for many more years to come, because it is very much needed.

www.stammering.org



Norbert Lieckfeldt

A word from the Chairman

2014 is a very significant milestone for the Barker family and everyone associated with the Trust. It marks 20 years since Dom Barker, who had a persistent stammer, took his own life at the age of 26. This tragic event sparked the idea of a charity dedicated to funding research into stammering, its causes and treatment. This issue is almost entirely given over to our research partners and collaborators and tells you about the work that we have funded and the impact the Trust has had on the stammering community since it was established in 1997.

I hope that you enjoy this issue of the Newsletter. We are hugely indebted to our supporters and fundraisers. Some have run up mountains and others have bought Christmas cards but everyone has contributed to the work of the charity, which continues to make real progress in finding practical treatments for people who stammer. We are enormously grateful. Thank you.



Toby Kramers



How this bird will raise funds for the Trust.

Turn to page 7 to find out.

Twenty Years On

By Eleanor Barker, Trustee

Dom's death 20 years ago was devastating for our family. We formed the Dominic Barker Trust to help others who stammer, and to prevent them from facing the same difficulties as he did. The Trust's objectives are to fund research into stammering; to raise awareness of the issues that surround stammering; and to encourage understanding in people who meet those who stammer. Importantly, we look for practical outcomes as well as contributions to the body of academic knowledge – and ensure that successive research builds on earlier findings.

From its local beginnings in Suffolk, the Trust has broadened its scope to include, amongst others, University College London (UCL), Leeds Metropolitan University and the University of Liverpool – and internationally, the University of Witwatersrand in South Africa.

Our first funding award went to Isobel Crichton Smith (Suffolk College) in 1998. This five year fellowship explored four areas: the Parent-child Interaction project; an investigation into Speech and Language Therapists' (SLT) attitudes to stammering; communication barriers and coping mechanisms used by adults who stammered; and the Play and Fluency Project (Page 4). In 2004 the DBT received an honorary degree conferred by the University of East Anglia (UEA) – an acknowledgement of the Trust's efforts in the region.

Building on this research, we funded Tammy Davidson Thompson's PhD at the UEA starting in 2005 and exploring SLTs' attitudes and best practice in working with adults who stammer. Her recommendations have been cited in a research synthesis produced by the Royal College of Speech and Language Therapists, directly influencing how services should be run. (Page 3)

In 2008 the Trust began funding the Early Childhood Dysfluency Project, based at University Campus Suffolk (UCS) with assistance from UCL. This ongoing longitudinal project, which looks at factors that lead to a persistent stammer in children, (Page 5), has subsequently led to a new investigation into parental attitudes towards speech therapy, which is vital if families are to support the therapy their children need. In 2009 further funding enabled Isobel to undertake the Star Talking project, assessing a particular play-based method



Eleanor meets Sarah Brown at a BSA reception at No 10

of supporting parents with dysfluent children at home before therapy becomes available at a clinic. (Page 4)

A PhD project looking at early intervention began in 2013, in collaboration with UCL, aiming to provide a screening tool for schools to identify children who are at risk of stammering and other communication disorders. (Page 4)

In 2006 we funded research into a piece of technology that could help people who stammer use the telephone more effectively. (Page 6) We are currently funding a pilot study analysing transcribed speech patterns of people who stammer which may reveal factors about their linguistic development.

One of the issues felt keenly by Dom was the attitude of potential employers during job interviews. In a letter to his family he wrote 'Every employer sees it as a problem. It's galling to find that your ability is not in question but that the stammer is.' It is apposite that 20 years on, we are involved in helping people who stammer at work. The work of Dr Clare Butler (Page 3) has provided important insight and understanding of the obstacles that need to be overcome in the workplace. The Trust is also very pleased to be involved in the Corporate Stammering Network initiated by the BSA and Iain Wilkie, senior partner in the management team at EY (formerly Ernst & Young LLP), to help employers create a culture where people who stammer can achieve their full career potential.

The Trust has also given practical support. In 2008 we provided video and laptop equipment to 13 SLT clinics in Suffolk to help with assessment, training and family interaction. We have funded seven Study/Open Days to enable SLTs

and researchers to share good practice and learn new skills; supported self-help groups across East Anglia and funded the presentation of papers written by researchers at The International Fluency Association, BSA and Oxford Dysfluency conferences, amongst others.

We are extremely grateful to all those with whom we collaborate – researchers, academics, donors, the BSA and other organisations representing people who stammer – without whose time and support this body of work would not be possible. We need your continued help to carry this work on. Although born out of a family tragedy, what has made it all worthwhile is hearing from researchers and people who stammer that the funding and work has made a real difference to their lives and experiences.

www.dominicbarkertrust.org.uk



Dom

RESEARCH SUPPORTED BY THE TRUST

Good practice

A report on the work at the University of East Anglia

Beginning in 2005 and building on Isobel Crichton Smith's earlier work, Tammy Davidson Thompson was funded to undertake a PhD at the UEA, under the supervision of Dr Jan McAllister. The aim was to explore SLTs' attitudes and best practice in working with adults who stammer.

As an SLT herself, Tammy felt that there was a lack of clear guidance and clinical trials to indicate which types of therapy were effective and therefore which therapy choices were most appropriate to meet the psychosocial needs of adults who stammer. Her research revealed fascinating insights and her results and recommendations have been recognised across the stammering community.

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.

Tammy's work was recognised with the prestigious Travers Reid prize 2011 for a research project on stammering, presented at the Michael Palin Centre.



Tammy Davidson Thompson receiving the Travers Reid Prize in 2011

Getting down to work

Report from Newcastle University

A study focusing on stammering in the workplace, undertaken by Dr Clare Butler of Newcastle University and funded by the DBT, found that people who stammer experience widespread prejudice in the employment market.

More specifically, the research has found that employers routinely discriminate against people who stammer, rejecting them because of concerns about possible negative reactions from customers or team members.

The findings were published in *Work, Employment and Society*: a leading international peer-reviewed journal of the British Sociological Association that publishes theoretically informed and original research on the sociology of work. With the support of the DBT, this research has raised the issue of stammering in the workplace and highlighted that employers have a responsibility to ensure that all employees - including people who stammer - have full access to opportunity at work so that they can realise their potential.

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Dr Clare Butler

Generation game

By Isobel Pickering (nee Crichton-Smith), Dysfluency and Voice Specialist for children in East Suffolk

In 1998, the DBT funded a five-year research project at Suffolk College Ipswich. Although the primary focus was the treatment of early stammering, the local response inspired a first study into the lived experience of stammering, highlighting the limiting effect that stammering can

have on the individual; the varied reactions to these shared limitations and common experiences. In 2002 'Communicating in the real world: accounts from people who stammer' was published in the Journal of Fluency Disorders (JFD).

I went on to investigate the Attitudes of UK SLTs towards working with people who stammer. A mixed picture emerged, with a decrease in negative attitudes towards working with people who stammer and an increase toward early intervention along with a strong need for SLT training. This work was published in 2003 in the International Journal of Language and Communication Disorders.

We went on to explore therapies for children who stammer based on five case studies on one of the most commonly used therapies of that time: Palin Parent Child Interaction Therapy. All five participants reduced their levels of stammering over time and four were able to maintain this fluency over the measurement period. An analysis was presented at the 2002 Oxford Dysfluency Conference (ODC).

We then researched children's speech and fluency during



Isobel Pickering



The Moss family try the Star Talking Box

imaginative play compared with more structured, rule-based games. It appeared that children stammered significantly more in free play than when engaged in imaginative play with a parent. This research was presented at the 2006 International Fluency Association conference in Dublin.

By then I had returned to work in the local NHS, but I continued to pursue the research that I had developed over six years working full time for the DBT, focusing this time on therapy for very young children who stammer.

The 'StarTalking' study looked at an entirely new therapy for very young children who stammer. Carried out at home by families using a take-home box of games and therapy manual, the feedback was predominantly positive.

Some children's stammering improved and no child's speech deteriorated. Parents liked the therapy but some found it hard to keep it up whereas the children enjoyed

the games. Adjustments to improve efficacy and increased contact with a clinician were felt to be helpful in overcoming some of the difficulties experienced.

An exciting adjunct of this therapy is a work book supporting fluency in very young children who stammer – hopefully to be trialled across Suffolk in 2015. 'Star Talking – the box of games' was presented at the 2011 ODC.

Without funding for these smaller scale studies much of this exciting and varied research would never have taken place and I would not have developed a therapy for young children. The DBT has also provided practical help and together these initiatives have improved the provision of therapy for children who stammer in the local area as well as contributing to the knowledge base on an international level.

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Child care

A report from University Campus Suffolk

Since 2008 the DBT has funded a number of research projects at UCS carried out by Sarah Costelloe (SLT and Research Associate) and Dr Steve Davis (UCL) under the guidance of Professor Penny Cavenagh.

All the research is aimed at improving outcomes for children who stammer. The main project, which started in 2009, sought to identify the risk factors associated with persistence of and recovery from stammering in childhood. Up to nine per cent of young children stammer in the pre-school years, yet the majority experience a complete and spontaneous recovery.

Finding out why this happens has practical implications for therapy. This longitudinal study will help SLTs identify which young children are at greater risk from persistent stammering into adolescence and adulthood, thus ensuring scarce resources are targeted appropriately.

Interestingly, the longitudinal study revealed that children who stammered performed significantly worse on IQ testing than those who didn't stammer, with anecdotal evidence suggesting this was due to lower attention levels rather than lower intelligence.

This resulted in a second study to identify attention deficits in children who stammer; the first to use an objective, direct measure - the Test of Everyday Attention for Children (TEACH) - rather than relying on more subjective parental reports. The results confirmed our 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. This fits in with current hypotheses about the causes of stammering and again has practical implications. It could be that some methods of delivering therapy may not be suitable for children who have these attention deficits. There is scope to extend this research

to investigate possible benefits in addressing children's levels of attention directly in therapy.

The latest piece of research was an on-line parent survey, in association with the BSA. It revealed that parental concern is extremely high, especially around bullying and their child's future prospects. Parents receive useful advice from the BSA and the internet but less so from professionals such as teachers and doctors. Views of speech therapy were also mixed. On the whole parents were satisfied with the assessment but less so with regular therapy. The positive experiences were associated with specialist therapists and successful programs such as the Lidcombe program and Parent Child Interaction Therapy. Negative experiences were associated with less experienced or non-specialist therapists and not being able to access therapy in a timely manner.

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Dr Steve Davis OBE



Professor Penny Cavenagh



Sarah Costelloe with Alfie

A good reception

A report from University College London

It is generally agreed that treatment for stammering and other speech difficulties is most effective if children see an SLT at an early stage, ideally when starting school, but this is neither practical nor cost-effective. Avin Mirawdeli's PhD, being carried out at UCL and supervised by Professor Peter Howell, allowed her to develop

a standard scientific procedure that teachers can use to identify such problems. It was based on work carried out in primary schools in London and Ipswich.

Her universally-applicable procedure involves teachers taking a short sample of speech and analysing this for nonfluent symptoms so that SLTs can then carry out a detailed assessment. It is important that the therapists are aware of the limitations and accuracy of the identification procedure so it can interface with their own diagnostic and intervention procedures – something which is currently not the case.

It has also emerged that children with

Professor Peter Howell



English as an additional language, may show word-finding difficulties that lead to nonfluencies. There is a need for procedures that distinguish such children from those with speech difficulties.

Commenting on the research, Cherry Hughes, BSA Education Officer said: "In my experience, teachers find speech issues a complex area to understand and evaluate and many children suffer as a result of a lack of support in school. When teachers are trained to use such a screening tool, with support, I would anticipate attainment levels to eventually become more commensurate with ability."

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Avin with one of her young participants.

Completing the jigsaw

By Dr Per Alm, Department of Neuroscience, Speech & Language Pathology, Uppsala University, Sweden.

Stammering was a part of my childhood. It was completely out of my control and fluency was always just out of reach. I was mystified. Is it just a psychological problem, or is there some complex physiological mechanism underlying these puzzling speech difficulties? Answering these questions was the aim of my PhD thesis - "On the causal mechanisms of stuttering" - at Lund University, Sweden.

With the support of the DBT, I embarked on a project focusing on both the emotional and the motor aspects of stammering. Despite the popular view that "emotional sensitivity" is typical in people who stammer, my research clearly indicated that children who stammer are no more shy or socially anxious than other children.

However, some children who stammer do show some traits of attention deficit hyperactivity disorder (ADHD). Temper tantrums may be reported as "emotional

reactivity" in research but the data does not suggest that emotional reactivity would increase the risk of stammering becoming persistent - if anything the opposite appears to be true.

The review of temperament and emotional reactions in relation to stammering was published in the *Journal of Fluency Disorders* (2014) along with an analysis of research on situational variability of stammering. It is proposed that the difference between talking when alone and talking in a social setting is mainly related to the extent of task-irrelevant thoughts/cognitions, and only indirectly related to emotional reactions, like fear.

The integration of research on motor aspects of stammering has resulted in a model of stammering as a "threshold disorder", meaning that the speech of a person who stammers may be close to disruption even though it is perceptually fluent - but the instability may still be



Dr Per Alm

perceptible for the speaker.

These theoretical models have laid the foundation for new empirical studies at the Uppsala University, Sweden, relating to speech motor disruption and brain activity related to speech and stammering.

To understand stammering it is essential to take time to build integrated models of the scattered and plentiful pieces of empirical data and for that I am most grateful to the DBT.

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Positive feedback

By Monica Bray, formerly lecturer at Leeds Metropolitan University

In 2006 just before I was about to retire as a lecturer at Leeds in (among other things) Disorders of Fluency, I was lucky enough to become part of the family that is Dom's Fund. Uniquely, Dom's Fund enables small-scale research,



Monica Bray with Ray Millar from Suffolk

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which may not have met the funding criteria from bigger bodies, whilst also providing an opportunity for researchers who are not attached to large research organisations.

This collaboration allowed me to explore the usefulness of a Telephone Assistive Device, developed by Alan Falck in South Africa. It delayed the feedback of the speaker's voice as he or she spoke on the phone thus inducing fluency for people who stammered and were particularly fearful of telephone use.

Despite my reservations about assistive devices, investigating further and seeing its usefulness in clients broadened my outlook. I was able to engage in qualitative research by visiting and talking to a number of people who stammered and discussing the technical details with Alan who was so able and enthusiastic.

The outcome was presented at the ODC in 2008 and published in the *International Journal of Speech-Language Pathology*. I am thankful to the fund for allowing me this opportunity and for furthering the knowledge base in the stammering field just that little bit more.

Moving mountains

We are entirely dependent on the generosity of our donors and contributors and would like to sincerely thank the very many individuals and organisations who have helped us. Mountains have been conquered, marathons, fun-runs, charity walks and bike rides have been accomplished; fundraising concerts have been attended, leaflets distributed and cakes have been baked. As well as keeping the money coming in, these efforts continue to raise awareness and help to create a greater understanding of the trials faced by people who stammer. Our supporters who have contributed since the last newsletter include:

Altorian - Bakers Arms Supper club - Bill Fone Pollitzer Charity - Boyton charity - City Gate Development Charity - Farrer-Brown Trust - Holbrook Gardens Angling club - Holbrook Gardens shooters - Holbrook Methodist Church - Holbrook Parish Council - Inner Wheel - Latterford Trust - Lavenham Lectures - Merlin School - No 10 District IAPS - Orwell Park School - Sir James Reckitt Trust - Sir Robert Gooch Trust - St Andrews Church Chelmondiston - Suffolk and North Essex Law Society - Suffolk Life charitable trust - Suffolk Lones - Suffolk Provinces Grand Charity - Willis Charity - Wolsey District Scouts

Christmas decoration

Few Christmas baubles can outshine the impressive plumage of our native goldfinch - the subject of our latest Christmas card. This stunning winter picture, taken by Suffolk-based photographer Russell Edwards, features on the front of our new greetings card, with an equally captivating picture of a pair of terns, immersed in their mating dance, on the reverse.

Measuring 15cm x 10cm and printed on quality card, the avian duo are also available on blank cards for your own message, for use throughout the year. Sets of Christmas cards and blank cards from previous years are also available.

Both can be ordered on line - with a donation of £5 for 10 cards - at www.dominicbarkertrust.org.uk



Chloe with her family

This year in particular we have to thank Trustee Chloe Chancellor, a friend of Dom's and her family who all completed the Alton Water Run in May, in aid of Dom's Fund. "We had a great morning in the wind and rain, running 37km between the five of us. We were hugely spurred on by the generous support of our sponsors. Dom's Fund has absolutely minimal overheads: no staff costs, no premises to pay for. Being a trustee has given me the privilege of seeing what a difference we can make to the lives of those who stammer."

Another childhood friend of Dom's, Emma Enderby, took part in the Cotswolds Way Challenge, walking four marathons in four days and clocking up a staggering 106 miles. Her trek was blessed with good weather and this and the views and countryside made up for the long days and inevitable aches and blisters. Emma wrote "Arriving in Bath Abbey at the finish line was unexpectedly emotional, as well as an enormous sense of achievement and pride that I had been able to raise awareness and funds for Dom's Fund."



Emma during her Cotswolds trek



Helen Barker receives a cheque from the Trefoil Guild

We are also very grateful to the Trefoil Guild for their generous donation: the funds were raised in a variety of ways by guilds all over the county, including a wonderful Christmas Tree concert at Stowmarket.

We take our swim cap off to Dom's cousin, Andrew King. Not only did he swim the River Arun (3.8k) in June - but he went on to swim the English Channel Relay - and once he had dried off and warmed up, presented us with a much appreciated cheque.

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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 Trust would not be possible without our Trustees who ensure the work of the DBT is carried out responsibly and cost-effectively and that it meets our 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. We would also like to take this opportunity to thank our former Chairman, Sir Malcolm Pill, and former Trustees Simon Wallis and Gill Garnham for their support and guidance to the Trust.



The Trustees, from left to right:

Guy Barker, Chloe Chancellor, Dr Chris Brown, Dr Sally Williams, Toby Kramers, Eleanor Barker, Ian Angus

The Trustees are grateful to:

Beverley Wigg for editing this newsletter (www.beverleywiggpr.co.uk)

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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 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
to help?
Dom's Fund

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