

Dom's Fund

CHALLENGING TIMES

A word from the chairman

These are difficult times for everyone and charities are no exception. Many have seen a reduction in their traditional income streams and given the economic impact of the coronavirus they may find future donations are lower than usual. At times like these we may find ourselves evaluating everything we do and inevitably some good causes may be more prominent than others as we contemplate where the need is the greatest.

At first glance speech disorders might not be an obvious priority but our ability to communicate with others is fundamental to our general wellbeing and our ability to earn a living. With unemployment on the rise, people who stammer face additional challenges as more people seek fewer jobs. We would like to think that they still have the opportunity to reach their full potential – and better still, to shine in their chosen fields. During the height of the lockdown we heard a great deal about isolation – and communication by phone or Zoom-style meetings is not something that suits everyone. We are determined to continue to support research which will make these situations easier to navigate for people who stammer.

At Dom's Fund, donations are used only to fund research and activities related to research projects. The Trust keeps overheads and expenses to a minimum, it has no employees, owns no property or vehicles and the administration is undertaken freely by Trustees and volunteers. There is little we can do to cut back so we must do everything we can to keep the funds coming in so that important research can continue. Like all charities we rely on the kindness and generosity of friends, colleagues and strangers and we are constantly heartened by the many loyal benefactors who have helped us over the years. We would like to take this opportunity to thank everyone for their support both in the past and in the future.



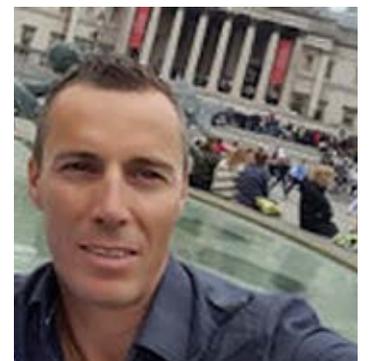
Toby Kramers

FRONT LINE RESEARCH

Assessing the impact of stammering in the NHS workforce

The NHS is keen to understand the particular challenges that face people who stammer in its employ and Dr Vaughan Parsons (PhD), research manager and research fellow in the Occupational Health Service at St Thomas' Hospital in London, is heading up a new initiative – funded by the Dominic Barker Trust (DBT) - to assess the impact of stammering in the NHS workforce.

Questionnaires were distributed at the beginning of the year to gather feedback from staff who stammer and by 1st July, 124 organisations had confirmed that they would promote the staff questionnaire although the exact figure could be higher. At the time of writing, 339 NHS staff who stammer had completed the online questionnaire and 24 NHS occupational health (OH) departments had completed the OH usual care survey. Inevitably, the study has been impacted by the coronavirus and following an extended deadline, further feedback is being gathered so that a final paper can be written up during October/November. Even with the data received to date, Dr Parsons is confident that there is sufficient information to conduct a meaningful analysis and to formulate important recommendations which will support people who stammer in the NHS workplace.



Dr Vaughan Parsons

NO SWANNING AROUND – CHRISTMAS IS COMING!

Continuing with our penchant to offer stunning wildlife photos for our double-sided greetings cards we will have a new design available this month. The front shows a swan with a 'piggy backing' cygnet while the back shows a clutch of cygnets forming an orderly line in front of the parent. The new cards are available with a Christmas message or as a blank greetings card – at £5 for 10. Previous cards are also available online.



Our latest greetings cards



MULTI-TASKING

Stuttering and attention

Two new research projects, investigating the link between developmental stuttering and attention, have been supported by the DBT in the past two years. These were devised by researchers from the University of Suffolk (UOS) which has been exploring the topic since 2013.

One of these projects is the first systematic review to look at the relationship between developmental stuttering and attention. The study was carried out by Dr Silviya Doneva (UOS) and included



Katie Tyrrell

21 suitable studies, conducted with adult people who stutter (PWS). The results from the meta-analysis showed that overall PWS performed significantly worse on attentional tasks compared to fluent speakers. Furthermore, stuttering was also associated with poorer performance on selective attention (focusing on the task at hand while ignoring distractors) and dual tasking (performing two tasks at the same time). The review, published in October 2019 in the International Journal of Speech-Language Pathology, has been very well received by academics and clinicians.

The second project has been designed to examine the attentional performance of children who stutter (CWS) – right after the onset of stuttering – along with children who do not stutter (CWNS). The focus will be on children between the ages of five and six. The project will be carried out by Professor Penny Cavenagh (Project

Supervisor, UOS), Katie Tyrrell (Research Assistant, UOS), Dr Silviya Doneva (Research Consultant, UOS) and Sarah Costelloe (Speech Therapist, NHS).

This study will build on the fact that both stuttering and attention develop simultaneously in early childhood and become more stable before the child reaches six years of age. Twenty CWS and twenty age-matched fluent controls will be recruited from schools and private speech centres in Suffolk and the neighbouring counties. Attention will be measured with a standardised attentional battery of tests, as well as through parent- and teacher-ratings. A 30-minute speech sample will also be collected from all children to establish stuttering severity in the CWS group and fluency in the CWNS group. The project will take a year to complete and it should start this month (September) now schools have reopened. It is hoped that this study will provide useful insights into understanding the disorder right at its beginning, as well as having practical implications for treatment. The team would like to thank the DBT for funding this research and give a special acknowledgement to one of the trustees, Dr Steve Davis, OBE (UCL) for his invaluable guidance on this project.



Dr Silviya Doneva



Professor Penny Cavenagh



Sarah Costelloe

MAKING IT WORK

Stammering in the workplace

A study, funded by the DBT and undertaken by Dr Clare Butler – Lecturer in Work and Employment, Newcastle University Business School - found that people who stammer experience widespread prejudice in the employment market.

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

Dr Butler's study was 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 raised the issue of stammering in the workplace, highlighting that employers have a responsibility to ensure that all employees - including people who stammer - have full access at work so that they can realise their potential.



Dr Clare Butler

SPREADING THE WORD

The 50 Million Voices initiative

50 Million Voices is a global initiative which aims to change perceptions of stuttering in the workplace and create a world where everyone who stutters can enjoy a rewarding working life. Launched in 2019, it brought stuttering leaders and key employers in 16 countries together to share ideas and best practice.

The initiative is led by Iain Wilkie, a leadership coach, former senior partner at global firm EY and founder, with Norbert Lieckfeldt, of the UK's Employers Stammering Network.

Activities include regular conference calls to build collaboration and trust; sharing good practice and communication tools and experiences connected to the pandemic as well as raising awareness amongst employers. The initiative has already seen tangible results such as support for Ghana in tackling prejudice and raising employer awareness, and helping Israel with its mentoring programme.

Amongst other things the group is planning to hold a Practice Interview Day for people who stammer, to be held on 22nd October in conjunction with the International Society for Affective Disorders (ISAD)

www.50millionvoices.org



Iain Wilkie

Speech Recognition

Automating a speech and language assessment

In the past two years, with the help of the DBT, the team at the University of Cambridge (UOC) - led by Dr Avin Mirawdeli - began investigating the possibility of automating a speech and language assessment for children aged four to six years. This will build on a successful web-application (an App), which already assesses children's language.

The DBT and the team at the UOC acknowledge the importance of technology in education. Its use in schools is on the increase according to research commissioned by the education technology charity Tablets for Schools. An automated speech and language assessment that works effectively and reliably and that is accessible through an App will therefore be beneficial for children, specifically those with speech difficulties such as stammering. The App's aim is to identify children who may benefit from intervention in their early school years.

In August 2019, Avin was awarded the prestigious and extremely competitive New Investigator grant from the Economic and Social Research Council (ESRC). As well as supporting Avin through the grant application, the DBT is continuing to fund this project by supporting the role of Bethany Jones, the research assistant on the team.

Avin says "This is an exciting time for speech technology research. As automatic speech recognitions for adult speech are consistently improving and perfecting recognition of phonemes, the opposite is true for children's speech and this needs improving, particularly as children's use of tech is on the rise. Although we were unable

to test children due to the Covid-19 lockdown, we are finding ways to creatively and effectively use earlier data to ensure we do not plateau in the development of an automatic speech recognition system.

"Without the support of the DBT we would not have secured the ESRC grant. Technology is expensive and the grant process demanding and time-consuming so the DBT's involvement has been crucial."

Bethany, who began work during the pandemic adds "I was excited to join Dr Mirawdeli on this project and grateful to the DBT. I will use my experience and knowledge to support children with stammering and other speech and language difficulties, by ensuring this speech difficulty assessment tool is developed without delay."



Bethany Jones

MAKING NOISE

Noises and voices study; review of popular therapy methods

Louise Helliker (UOS) – who is supported by her employer BT - has been working on a study which looked at the use of noises and voices in two groups of children. In the study 18 children stammered and 14 did not. It can be seen from the results that there are differences in the way the children use speech and language to convey certain moods, attitudes, personas and humour. In these recordings, 22.2% of the children who stammer (CWS) 'put on' voices in contrast with 42.8% of the children who do not stammer (CWDS), whilst 72.2% of CWS and 57% of CWDS made non-verbal noises, e.g. car engines, dinosaurs roaring etc. This demonstrates that children who make noises, but are less likely to use different voices, are using sounds to express themselves other than through the medium of speech.



Louise Helliker

Louise has also reviewed two popular therapy methods and carried out a brief literature survey on the language abilities of children who stammer:

The Palin Parent-Child Interaction (PPCI) and Lidcombe methods of stammering therapy

Evidence shows that parents are happy with PPCI with their children enjoying the prescribed 'special times' in which PPCI is practised. However, like the Lidcombe method, it relies very much on parents spending regular periods of time dedicated to one child, uninterrupted and relaxed. Working parents, single parents, those families with other siblings or family members with special needs could find this quite challenging. Further research is under way at the Whittington Health NHS Trust/Michael Palin Centre – into the effectiveness of PPCI in the 8-14 age group, in comparison to a control group who will continue to receive their usual speech therapy.

Role Play

CWS are less confident in using their voices in a dramatic, playful or fanciful way, or taking on a different persona. As this ability could be very useful for them in the context of foreign language lessons and interviews it is recommended that speech therapists and parents encourage role-play and integrate it into each play/therapy session.

Vocabulary size and language ability

Several studies show that stammering tends to start when a child's vocabulary is increasing rapidly and children who recover from stammering go on to have good linguistic skills in general. There is greater variability in linguistic ability in the persistent stammering group. This may mean that persistent stammering is caused by other factors such as genetics, instability in dopamine receptors at pre-school age - particularly in boys - and Attention Deficit Hyperactivity Disorder. Speech is a complex motor control system and, in some people, it is slightly more unstable or sensitive than in others, so concerns about losing that control and about the reactions of others may be enough to destabilise it. This might also explain why we all experience dysfluency occasionally.

FUNDRAISING

LOCAL KNOWLEDGE



The view from RHYC

We had a fantastic turnout of sixty-two eager quizzers for the Dom's Fund Quiz Night in April last year held in the stunning Royal Harwich Yacht Club. Fortunately for those struggling with the questions the wonderful river views were a welcome distraction! Toby and Susie Kramers ran the quiz like professionals, with excellent questions fired out at a cracking pace to keep everyone on their toes. The competitive spirit ran high, but good sportsmanship prevailed and the atmosphere was very cheerful from start to finish. A big thank you to Toby, Susie, the RHYC staff and everyone who took part and helped raise £1800 for Dom's Fund.

LA GRANDE MARCHE!

Hats – or should we say 'chapeaux' – off to Dom's nephew William Barker and Freddie Horler who walked from Paris to Pangbourne in aid of a number of charities including Dom's Fund.

It took them seven days to walk 240 miles – starting at the crack of dawn to avoid the worst of the summer heat – and staying in B&B's along the way. "It was tough going but due to a resurgence on the final day we managed to finish with two hours to spare, with the final few metres coming down to a photo finish" says William. "We were immensely proud of our achievement and we even managed to remain on speaking terms!"



ON THE RUN



Dr Avin Mirawdeli – from the University of Cambridge - and her colleague Helena looked surprisingly relaxed after completing the Asics London 10K run last year in aid of Dom's Fund. All major roads were closed along the route, allowing them to enjoy some of London's most famous sights. Helena finished in under an hour and Avin in over an hour. Not bad going!

A CLOSE SHAVE

We've got to hand it to Craig Harvey who was prepared to lose four years of beard growth for the Fund. He likened it to losing a limb – but assured us 'it was worth it!'. Craig – a family friend and fellow attendee at the local Holbrook Methodist Church, which also does a great deal for the Trust – is a great supporter of Dom's Fund and his sacrifice was much appreciated.



BEFORE



AFTER

PEAK PERFORMANCE



In October 2019 Ollie Barker (also one of Dom's nephews) named Dom's Fund as his chosen charity in a school fundraising adventure named 'Summit 500'. A group of 75 teachers and pupils – cheered on by teachers and classmates - walked a route covering eight of the Brecon Beacon peaks, collectively climbing well over 500 summits! Given the personal connection, it was an especially memorable day for Ollie who said he 'was pleased to support the important work of the Trust and raise funds that will ultimately help reduce the shame, prejudice and ignorance around stuttering.'

At the time of writing Ollie is preparing to 'walk the Monopoly Board' in aid of Dom's Fund. He plans to visit all the iconic streets around London, hopefully staying out of jail! His friend Freddie Rock will join him and they estimate they will walk around 41 miles over two days.

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 BSA,
now called Stamma

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 EMAIL: enquiries@dominicbarkertrust.org.uk
- BY POST: Send a cheque using the slip below.
- BY PHONE: 01473 328530
- TWITTER: @stammerresearch

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.

ON THE SUBJECT OF PRIVACY

General Data Protection Regulations 2018 - Privacy Notice

The above Regulations came into effect on 25 May 2018, and this notice is to reassure all supporters, volunteers and grant applicants that your data privacy is protected. We hold only personal names, contact details and information about donations to and grants from the Dominic Barker Trust. All this information has been volunteered by you and is held by the trust for administration in order to support research into the causes of stammering. The trustees will not use this information for any other purpose (or disclose it to third parties) or hold it for longer than necessary. If you would like to know about the data we hold, or to amend or delete it, please contact the trust in writing or by email: enquiries@dominicbarkertrust.org.uk

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you like
to help?

Dom's Fund

If you would like to make a donation, please complete this form and send it to:

Dom's Fund, Pound Close, Harkstead Road, Holbrook, Ipswich IP9 2RA.

I enclose a donation of £..... (Please make cheques payable to the Dominic Barker Trust)

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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