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# The Stammer Trust

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NEWSLETTER



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## EDITOR'S NOTE



Welcome to our newsletter.

As this newsletter drops on the doormats it's no surprise that we start focusing on taxes with slim hope we might get some money back from the government. One way the Stammer Trust can benefit from the government is by our members opting in for **Gift Aid**. According to HMRC, **Gift Aid** is one of the most important sources of income for charities and is worth over £1.2 billion to the charity sector. Yet, each year £560 million in **Gift Aid** goes unclaimed. Charities could do a lot with half a billion pounds!

The Government allows charities to claim back tax on donations. This tax relief is called '**Gift Aid**'. If you're a UK taxpayer, whether on earned income or on savings income, **Gift Aid** increases the value of your charity donations by 25%, because the charity can reclaim the basic rate of tax on your gift – at no extra cost to you. For every £10 membership donated, the charity currently receives £12.50 when you add **Gift Aid**.

Gift Aid Awareness Day took place last October, with the aim of raising awareness among charities, staff, volunteers, donors, friends and families with a '**tick the box**' campaign. You can give more with **Gift Aid** and make your donation go further at no extra cost to you.

Currently only half our membership has signed up. So, if you haven't '**ticked the box**' and signed up for **Gift Aid** please download the form from our website or email the membership secretary at [membership@stammertrust.co.uk](mailto:membership@stammertrust.co.uk) Thank you.

If you have any comments, contributions or articles you would like to see published please send them to me by email to [newsletter@stammertrust.co.uk](mailto:newsletter@stammertrust.co.uk) before 4th October 2019.

Happy reading.

**Andrew Barnes**

Find us on Facebook: [www.facebook.com/StammerTrust](http://www.facebook.com/StammerTrust)

## FOREWORD FROM THE CHAIR



**T**he mini heatwave in February was followed by snow. The daffodils in our front garden looked rather confused, started to flower, got battered by a hurricane, but now look rather picturesque. A true example of recovery from challenging circumstances, and possibly something we all know something about?

At our AGM in November we were pleased to review the applications for the 2018 Terrence Barry Grant Award Scheme, making grants to the most deserving applicants. We are pleased that Capt Jack Horner has accepted a nomination to join our committee. Jack is now setting his eyes on a further endurance challenge, Race to the Tower.

At our March committee meeting Mahmoud, one of our recent grant award recipients, gave a presentation and led a stimulating discussion on his research comparing aspects of stammering and dyslexia. Mahmoud is seeking volunteers for assessment at Birmingham.

Jordi and his team at **Respira** have developed their device which monitors heart rate and breathing and feeds back to the wearer via a mobile phone app. Pre-beta trial testing of volunteers is currently taking place – please see details in this newsletter if you would like to participate.

This year's **Open Afternoon** will take place on Sunday 23rd June starting at 2 pm. We plan to hold a demonstration of the Respira device by Jordi and an interactive discussion led by Catherine, a therapist putting on a play in Oxford in the Autumn. "Unspoken" is a play which will enable audiences to understand what it feels like to stammer by sharing in the experience of a particular individual who is trying to overcome and come to terms with his stammer. We will have a chance to discuss progress on planning the play and input our own experiences. Tea and cakes will be served. All are welcome to attend.

**Andy McCabe**

## **THERAPISTS REPORT**

Referrals to the **Children's Service** have remained consistent. I must pay tribute to the wider Speech and Language Therapy team which has been very supportive, volunteering to help on groups and sending through appropriate referrals to the Apple House. I have seen children individually and last week ran the first of this year's groups: The Smoothies course for children aged six to eight. This was a lively group and parental and child feedback was encouraging. One child said that she wished she had come on a group sooner as it was 'really helpful' to meet other children who stammer. Once again, I am struck by the power of peer support when running group sessions. The next group to run will be in the Easter holidays, for children aged 9 to 12.

For the first time I have a final year undergraduate student from Reading on placement with me this term. I generally offer placements for the intensive courses as this has always worked well; this term, however, the student is working with me weekly. She has been able to see several different clients thus far, from young children following the Lidcombe Programme, to teens. She is also working independently with one child, aged 10, providing weekly therapy for her at the Apple House. This is proving a great success for both the child and the student! It is great for the student to have a client to focus on, planning and delivering therapy, and the child is benefitting from receiving regular 1:1 therapy over several weeks.

Finally, I must thank Chris for all her hard work in arranging the new filing cabinets. They look great and are such a pleasure to use after the old, rusty ones. Thank you to the Stammer Trust for all that you do to support our work at the Apple House. It is these details that make such a difference, and which are appreciated daily.

### ***Rachel Kennell***

*Highly Specialist Speech and Language Therapist, Clinical Lead for Dysfluency*

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The **Adult Service** continues to provide a range of therapy options to help people with their speech fluency. Referral numbers were down over the last quarter of 2018, but have picked up significantly since January 2019. At the moment I have eight people in direct therapy with a further 3 on the waiting list. With 2 days per week, this is a manageable caseload.

As before, my standard practice is to see people for hourly once-weekly 1:1 sessions, with clients joining 2-day follow up groups when the individualised aspects of therapy have been established. However, this is not the only format used.

I know this is a recurring theme in my reports but it is one I cannot stress often enough: different adults who stammer benefit from different approaches. The best outcomes arise from approaches that do not necessarily fit discrete 'therapy programs' where practices are relatively inflexible and followed through in stepwise fashion (regardless of individual variables from start to finish). Instead we develop, together with the client, plans that meet their specific needs.

For example, I am currently organising a complete day of 1:1 therapy for a person who has longstanding problems with severe stammering, and who has received only limited practical benefit from strategies that can work well but only in unchallenging settings. I believe this person will benefit from an intensive day and then follow-ups. It is very rarely that I see one person for such a long period, but I believe this will be the best opportunity to translate fluency control across a range of speaking situations, and to help fluency techniques to become more 'ingrained'. Again, the flexibility afforded by the stammer service at the apple house makes this possible. This person should have attended the intensive day a few weeks ago but illness has meant we have had to postpone. I will ask this client to feed back to the stammer trust to let you know how things went when we have rescheduled.

Consistent with this theme of individualised therapy, but in contrast to the example above, I find that I am spending an increasing amount of my time working with a counselling element to the forefront (incorporating, for example, mindfulness and cognitive behavioural therapy concepts), with fluency enhancing techniques as secondary factors. The paradox is that for some people it is the fear of stammering that is the more significant factor than the stammering itself. Manage the fear/anxiety and the avoidance and escape behaviours start to dissolve. This leads to an increase in confidence and with it often a spontaneous increase in levels of fluency.

With thanks as always to the stammer trust for your fantastic support,

**David Ward**

*Speech and Language Therapist*

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## FUNDRAISING



Last summer saw Captain Jack Horner complete the gruelling Race to the Stones, ultramarathon, 100kms in total across the oldest footpath in Britain 'the Ridgway' raising money for the trust. This June he plans to complete another ultramarathon. Race to the Towers is a similar style event (hard), it runs from Gloucestershire to Worcestershire along the Cotswold Way finishing at the magnificent Broadway Tower. The route is a total distance of 52.4 miles (a double marathon) and will climb up to 7, 476ft. Jack plans to do this over 2 days (26 mile per day). For more information regarding the event go to [www.racetothetower.com](http://www.racetothetower.com) – a fundraising page will be set up and made available for contributions in the up and coming weeks.

# TERENCE BARRY GRANT AWARD SCHEME

At our AGM last November applications were reviewed and discussed for the Terence Barry Grant Award Scheme after being advertised in the RCSCT 'Bulletin' and the BSA website. Seven applications were awarded up to the maximum of £250. The successful applicants were:-

**Roz Coe** a Speech and Language Therapist from Edinburgh - to attend a training course 'Working With Adults Who Stammer'

**Mahmoud ElSherif** a Psychology researcher studying at the University of Birmingham - to continue the study looking into links between stammering and dyslexia.

**Saraphir Qaa-Rishi** a stammer since childhood and movement teacher looking to attend a mental wellbeing course to promote a positive outlook / wellbeing for stammerers.

**Heather Roberts** a newly qualified Speech and Language Therapist in Birmingham - to attend a Michael Palin training course 'Using Acceptance and Commitment Therapy with Children'.

**Lucy Elliott-Lyall** a Speech and Language Therapist (Bucks) - to attend a 3-day training course at the Michael Palin centre.

**Emily Yagmur** a Speech and Language Therapist in Peterhead - to attend 'Working with Adults who Stammer' in Derby.

**Max Gattie** a PhD research student undertaking "The role of misidentification of own speech in persistent developmental stuttering"

Over the next few issues we will publish the reports from the applicants which give an insight into how the award has benefited them. We start with reports from **Mahmoud Elsherif**, and **Lucy Elliot-Lyall**. Mahmoud gave a presentation at our last committee meeting and recruited several volunteers to help with his research.

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## Report by Mahmoud Elsherif

### **Dyslexia and stammering: Do they share a processing difficulty?**

I would first like to give my profound thanks to the Oxford Stammer Trust, whose grant enabled me and my supervisors to recruit people who stammer for my study. In addition, I wish to extend my gratitude to the Trust for inviting me to present my research and for asking volunteers to participate in my research. The aim of this research is to compare the similarities and differences between people who stammer and those with dyslexia. We found that 43% of people with dyslexia had a childhood stammer. Next, we compared people with dyslexia who stammered in childhood and those who did not stammer as a child in a number of individual tests. We found that these two groups did not differ in measures of phonology, orthography and semantics, except for spelling. This indicates that people with dyslexia may share a processing difficulty with people who stammer. The grant would further enable me to recruit a larger population of participants who stammer. Recruitment is currently ongoing, albeit it is challenging to recruit people who stammer. I am planning to visit other stammer groups around the UK to increase the number of participants involved in my research.

Members of the Oxford Stammer Trust found my presentation interesting and thought-provoking, reporting that they had learnt more about dyslexia, along with the similarities between people who stammer and people with dyslexia. Furthermore, they informed me that a high quality discussion had ensued after the presentation. The feedback I received from people who stammer, and speech-language therapists was beneficial to my current thinking in the field. The Trust has asked volunteers in the group to participate in my study and for me to return in June to recruit more volunteers, as they felt the research would benefit not only people who stammer, but also people with dyslexia.

As a result of the meeting and presentation, I have recruited at least four people who are interested in becoming involved in the research. I hope that my study raises further awareness of dyslexia and stammering, something that could not have been achieved without the funding from the Terrence Barry Trust. I like to give my thanks to the Oxford Stammer Trust for the money that was provided and their support with advertising my research to help recruit more people who stammer. We hope the findings will be published in a high impact journal to help a variety of stakeholders understand more about these difficulties and advance the research into stammering and dyslexia.

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### ***Report by Lucy Elliot-Lyall***

I have recently been fortunate enough to benefit from the funding of the Terence Barry Grant Award provided by the Stammer Trust. The award supported me in attending a three-day training course provided by the Michael Palin Centre. The aim of the training course was to develop participants' knowledge, skills and therapeutic approaches to realise the potential of secondary school children who stammer.

I have been working within the Buckinghamshire Dysfluency service for approximately eight years. During this time, I have attended formal training and learnt from colleagues how to support pre-school and school aged children who stammer and their families. More recently I have begun to work with older children, teenagers and young adults who stammer and have been supported by the dysfluency clinical lead, who sadly will soon be retiring from our service. This departure posed the potential for a large gap in our services' ability to provide a therapeutic provision for secondary aged students.

As part of my appraisal and continued professional development I identified that I would like to further develop my knowledge and skills of working with secondary aged students who stammer. By doing so this would ensure that our service would be able to continue to support teenagers and young adults within Buckinghamshire who stammer.

Over the three days there were many learning opportunities which I engaged in and built upon my current knowledge of stammering and how to support young people and their families. I regularly conduct parent questionnaires as part of the assessment process in my therapy. During the course I found it beneficial to review and practice creating and explain a formulation following a questionnaire. Via the lectures I learnt new research data and ways to feed back information from the questionnaire in the formulation. From working with colleagues, I have gained some insight into approaches such as block modification, however, the majority of this learning has been via informal chats.

As part of the course, focus was placed on learning direct stammer shaping techniques via a combination of; video examples, lecturer demonstrations and therapist practice with feedback being given following each technique. I found this type of learning very beneficial, as I now know which approaches to use and when and have developed a 'script' of how to introduce these to my clients.

The Michael Palin Centre course was not only a fantastic learning opportunity but a great way to meet other therapists and discuss/share service delivery and therapy approaches. Through these conversations with other therapists my colleague and I have identified several adaptations to our current practice and service delivery model that would benefit our clients. Such changes could enable clients to access our service more rapidly and provide opportunities for teenagers to access groups where they can meet other young people who stammer.

Over the course of this year I hope to set up a group for teenagers who stammer and a support network for their parents. Since attending the course my colleagues and I have met with other members of our team and we are beginning to review our care pathway and therapeutic approaches with a view to incorporating learning from the course in to our practice.

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## **WHAT HAVE WE BEEN DOING?**

As a member you will know that your Committee meets 3 times a year - in The Apple House – February, June and November (which is also the AGM). And we discuss a number of issues. Our main aim is to support the Speech and Language Therapy service to adults and children in Oxfordshire who stammer. Andy (McCabe) our chairman and Andrew (Barnes) Newsletter Editor give you information in this Newsletter.....here is a bit more from me – one of your Trustees.

We lease the Apple House from the NHS Trust which runs the Warneford Hospital. But we 'look after' the inside of The Apple House – which remains a unique, unusual, attractive, safe environment for adults and children and their families to come to.

So the charity - The Stammer Trust supports the Speech and Language Therapy team in on- going training, attendance at conferences. It provides equipment - e.g. a new printer, a television to view recordings; books and resources / games which help therapy. We also pay for decoration of the interior.

So recently we have replaced the very battered/ hard to open filing cabinets in the entrance hall way. These keep hard copy client information secure and safe. There are now two gleaming white filing cabinets in situ. And we will arrange for a decorator to repair and paint the crumbling wall inside the downstairs cloak room. Some long term members may recall that the cloak room and hall way were an addition and were built on to the original building.

Our meetings are very informal and interactive and usually quite short - they usually involve cake or goodies. Do join us if you would like to - what we do benefits from all brains!

**Chris Charles** - Trustee

## THE VALUE OF A SINGLE PENNY

It was the Spring of 1992 when I was fortunate enough to attend a ten-day intensive fluency course at The Apple House. Before the course I was really struggling with my speech, stammering on practically every word, finding it very difficult to string a coherent sentence together, with my speech also rising up and down in volume as I could feel my levels of tension rising. There was no doubt about it, I considered myself to be a stammerer with very occasional patches of fluency. I remember being so unhappy, miserable, fearful of speaking and angry with myself for not being able to control my speech. I considered the intensive course as last-ditch attempt to gain fluency.

As the nine attendees all stammered in a different manner, we were given different fluency techniques and coping strategies where mine were slow, steady and paced speech, soft contacts especially on the more plosive sounds like b, p, d, t, etc. I also needed to tend to my breathing, ensuring that I had a good breath of air before starting and not being afraid to pause and take a top of breath when I felt that I was starting to run out of air. The initial four days were spent practicing our new fluency techniques but on the fifth day we were given a stack of ten, one pence pieces and were told that every time we fluffed our speech and could have employed our fluency techniques, we had to give up a penny. All my pennies were gone within the first hour, we were given a new stash in the afternoon and told to look after them like we should be looking after and cherishing our speech.

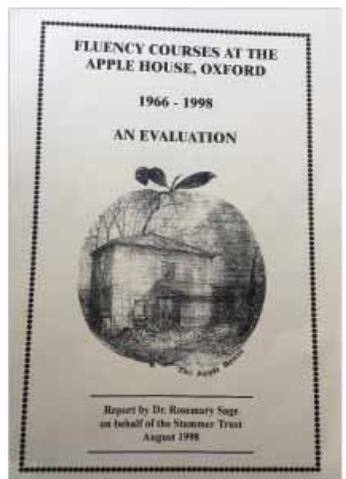
The following day, I made a real determined effort not to give up any of my pennies but lost a couple towards the end of the day and it really felt as though I was giving away part of my soul. On the seventh day, I began to monitor and judge myself from when I had a chat with the newsagents in the morning, spending all day speaking at The Apple House, using the telephone chatting with my parents that evening and felt that I'd hung onto all my pennies that day. For the remainder of the course, I retained all my pennies and knew from that day onwards I had finally conquered my stammer and was now in control of it rather than it controlling me. After the course I kept my ten, one pence pieces and drilled a hole in one to keep on my key ring to remind me of the day that I achieved fluency and gained control over my speech.

Fast forward many years to the present day and I consider myself to be a fluent speaker with an occasional stammer. I still employ all the fluency techniques but feel that I've now gone into automatic pilot mode. I've been using them for so long that I don't need to think about using them and the techniques have become a natural part of me, they kick in automatically and it's now such a real joy to speak.

Geoff Forward  
*Custodian Trustee*

# A STEP BACK IN TIME

As current Secretary for the Stammer Trust, I have been looking after the document 'Fluency Courses At The Apple House, Oxford, 1966-1998. An Evaluation'. A report by Dr Rosemary Sage on behalf of the Stammer Trust, August 1998, for a few years now. I have finally found time to have a flick through and think there may be some areas of interest to share with you. This extract falls under the heading 'The course of stammering through history'. The content within the apostrophes is lifted directly from Rosemary's report. The rest is my summary of her work.



'As far back as 2500 years ago, Laotze, the Chinese poet, mentioned stammering in one of his poems. A well known recorded example of the condition occurred around 1200BC in the second book of the Judaeo-Christian Bible, when God calls on Moses to lead the Israelites out the wilderness. In the Kings James version (1611) Moses says: 'I am not eloquent, I am slow of speech and of a slow tongue...' Although this is not a basis for claiming that Moses had a stammer, a passage in the Koran refers to one of his prayers: 'O Lord, unloose thou the knot in my tongue, that the people may understand my saying...'

By the time of the Ancient Greeks, stammering was commonplace (Compton, 1993). Herodotus wrote of it in 400BC and Aristotle a hundred years later. The most famous stammerer in history has to be Demosthenes, who was successfully treated by the actor Satyrus, orating with his mouth filled with pebbles and running up steep hills carrying heavy weights.

The Romans were so used to the idea of stammering that a family name, Balbus refers to the condition. Similarly, in the 9th Century, a Frankish King was known as 'Ludwig the Stammerer'. At this time, the Arabian doctor and poet, Avicenna, wrote in detail about causes and treatment which were unremarkable when compared with those of the Greek physician, Galen, who recommended that the tongues of those who stammered should be cauterised. This established the idea of pain and punishment to eradicate the stammer which persisted into the Victorian times.

Nevertheless, others took a softer, more humane line. Dr Mercurialis in the 1580s prescribed a calm life, regular bowels, and vigorous exercise. Francis Bacon wrote in the 1620's: 'The cause may be...the Refridgeration of the Tongue...And we see that those that Stut, if they drink Wine moderately, they Stut lesse, because it heateth.' (Compton, 1993).'

A Frenchman in the 1700's advocated severing the frenums (the membrane which connects the tongue to the mouth floor) of stammerers and piercing their tongues with hot needles. Many died in agony from such procedures.

Jumping forward to the 1800's, Doctors promoted laxatives, leeches on the lips and eating goats faeces! Thirty years later, Dr Frank recommended nothing more than a good flogging. The Finns concocted a vile smelling ointment called Hirven Sarven Tippola (Elk Oil Drops) for the throat. 'Other cures included Poett's 'Stammering Trumpet', the application of electric shocks to the spine, steaming the throat with aromatic herbs and learning the German language (Compton, 1993).'

Moving on to the 1900's things finally started to change for the better and Rosemary Sage explains that after a few decades of being considered a nervous disease, stammering began to be treated more as it is now with speech therapy. She goes on to say:

'In the post-war years, progress in understanding and treating stammering conditions has continued and accelerated. This has been spear-headed by organisations like the British Stammering Association. Linked to these groups is The Stammer Trust, which brings together those associated with the Apple House Fluency Courses, run at the Warneford Hospital, Oxford. The newsletters, information and activities generated by these support groups has played a crucial role in highlighting important issues for future planning and progress. This report is a clear example of the will to move forward and discover more precisely how to help persons who stammer.'

So, a snippet of the report considering Stammering throughout history. I will read on and let you know what I find.

Lisa Ellett  
Secretary

**OPEN AFTERNOON**

**SUNDAY 23rd JUNE at 2pm**

**Interactive Discussion & Workshop**

**led by Catherine Woolley, a speech and language therapist,  
whose play "Unspoken" comes to Oxford in October**

**Presentation & demonstration  
of the progress of the Respira project**

**Afternoon tea and cakes**

# WE NEED YOUR HELP

*(for building a Self-supervised fluency therapy for people who stammer)*

My name is Jordi and I am the founder of [www.respira.io](http://www.respira.io). We are developing a biofeedback device and mobile app to monitor breathing, speech patterns, and provide real-time feedback and performance history tracking, assisting people who stammer (PWS) in out-of-the-clinic scenarios. In the Winter newsletter, I wrote about our difficulties obtaining public funding to keep the project moving. Fortunately, I can say this bad luck has drastically ended.

We are pleased to announce that we have just won two grant competitions from the main organization supporting Research and Innovation in the UK (InnovateUK). The combined grant money of £330k includes:

- Around £100k for a clinical study with the University of Reading (lead by David Ward).
- £5k to be given to the Stammer Trust for its unconditional support to our project. A small portion of this grant will be spent for the SLTs from the Stammer Trust travelling for the project meetings from and to London.
- Support from the British Stammering Association to recruit participants and help as an advisory member.

Before we start the official clinical study with the University, we are conducting early tests this month of the hardware prototype with PWS. It is a test of approximately 30 minutes (10min of preparations and 10-15 minutes of testing) in which participants will run through a few speaking exercises.

The early testing is going to be performed in the London and Oxford area (i.e. Apple House). Would you be able to help us by participating in those tests? I would be extremely grateful if you (or someone you know) could contact me at [jordi@respira.io](mailto:jordi@respira.io) to express your interest in participating in the test. By participating in this early testing you will also have the chance to join the clinical study this Fall if you are interested.

We are incredibly grateful for the support we have had from the Stammer Trust, especially for being the first ones to believe in us by offering the Terence Barry Grant Award. That's why we thought that providing £5k to the Stammer Trust was a good way to say thank you. We hope these resources will be useful for the Stammer Trust to keep helping PWS around the UK.

We need your help to develop a self-supervised fluency therapy, which we hope to help thousands of people in the UK (and millions of people around the world). If you aren't able to participate in the testing at this time, please watch out for our mobile app launch in a few months and help spread the word to other PWS.

Track and change your speaking and breathing habits in real time.

WE NEED YOUR HELP

 **Respira**  
For People who stutter

WE ARE RUNNING THE FIRST PRE-TEST ONLY IN MARCH.  
THIS IS YOUR OPPORTUNITY TO RESERVE A PLACE IN THE  
CLINICAL STUDY WITH THE UNIVERSITY OF READING TO BE  
RUN IN LATE 2019