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# The Stammer Trust

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NEWSLETTER



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## EDITOR'S NOTE



Welcome to our newsletter.

It's always pleasing to see stammering kept in the public domain with documentaries on television, famous people sharing their experiences and organisations such as the British Stammering Association promoting awareness. Social media also helps to play an important role which was seen recently with International Stammering Awareness Day (#ISAD2018) held annually on 22nd October. Stammers across the globe were able to connect via Facebook and Twitter. I saw an article regarding Fluency in the Workplace together with an advert from EY (formerly Ernst & Young) which I thought is a worthy read and have been given permission to publish. Make a note of the date in your diary for next year.

Recently I met an acquaintance who told me his daughter is away at university studying speech & language therapy. While speech & language therapy is diverse providing support for children and adults not just for stammering but also eating & swallowing conditions, strokes, head injuries and degenerative conditions etc, it is encouraging to learn that young people are still keen to join a profession that receives a small portion of the NHS budget while organisations, such as ours, rely wholly on donations and subscription membership.

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 15th March 2019.

Happy reading.

**Andrew Barnes**



**#ISAD2018**

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

## **FOREWORD FROM THE CHAIR**



I look out the window and see more leaves waiting to be cleared away. The sunshine makes it look as though it should be warm outside, but possibly deceiving? The hour is about to change, then it will be dark when I leave work. I now have the delight of reading the draft version of this newsletter.

I recently met Capt Jack Horner, and heard first-hand about his 100 km endurance marathon, Race to the Stones. Surely something we would all like to be fit enough to aspire to undertake, but perhaps we aren't in such good shape? Our thanks go to Jack for his splendid fundraising for the Stammer Trust.

Ray has written from experience a thoughtful article on the challenges of stammering. Well worth reading. Then an article on fluency in the workplace by the founder of the Employers Stammering Network. I regularly take part in web meetings with participants in Europe, USA and sometimes the Far East. A bit daunting at first, but a few strategies and it becomes a very useful tool – as long as we can find a time which suits everyone. I still prefer to jump on a plane a few times a year and visit people. Old fashioned I know, but really useful. I'm pleased my boss agrees.

Jordi's article on the development of the Respira device is a timely illustration how our grant award scheme can encourage the development of such ideas and catalyse further funding and progress further development. The 2018 Terrence Barry Grant Award scheme has run again this autumn. The applications will be discussed at our AGM, and grant award recipients notified soon afterwards.

I invite all of you to attend our AGM on Saturday 10th November at the Apple House. We start at 12 noon with a light lunch, and aim to finish our reports, review and discussions by 3 pm.

***Andy McCabe***

# **ADULT THERAPISTS REPORT**

The beginning of the year was rather disrupted by my extended sick leave of absence which saw me away between February and early May. Fortunately, this happened to coincide with a lull in new referrals, so although the clients who I was seeing at the time were delayed, the waiting list did not build too heavily and I was able to catch up soon after my return.

## **Therapy strategies**

More and more I find myself drawn toward individually-tuned therapy procedures. There are established programs for management of stammering in adults (for example, the Camperdown program) and these can be effective, but such fluency shaping approaches don't suit everybody. Some people come with very focussed ideas as to what they want and it is important to listen to these and then to collectively develop a plan that addresses the issues rather than everyone working to outcome measures determined by clinicians. Once those goals have been identified, the focus is on how can we deliver maximal changes toward achieving these goals with minimal effort from the client. We all know that almost everyone can become nearly 100% fluent, but for the vast majority, the techniques required to achieve this can themselves be arduous, require constant practice and ultimately, speech may not sound natural and/or slow. In addition, it may simply not be feasible to implement these techniques constantly and across all speaking situations. For some, it might be easier, less effortful and more comfortable to 'stammer fluently' and without tension than to work on maximal fluency control. For others, losing the fear of stammering might be a bigger goal than working on any type of control strategy. Everyone is different, and these differences must be addressed effectively in therapy.

I continue to run the 2 day follow up programs – a system which feedback tells me is working well for attendees. Courses ran in January and again in June and there will be a further one later this year. The nice thing is that following the individual 1:1 work this provides an opportunity to test different practices, including different levels of fluency and different end goals, as mentioned in the last paragraph, in a range of real life situations. So while it is a group – there is still 1:1 focus on individual needs. Being able to cherry pick high quality SLT students from the University of Reading working on these course really helps with being able to deliver focussed help within a group setting.

## **Talks & presentations**

Earlier in the year I was invited to give a lecture at the Bi-annual Symposium of the European Clinical Specialism in Fluency Disorders [www.ecsf.eu](http://www.ecsf.eu) in Antwerp. The ECSF provides a 1 year specialist qualifying program for qualified clinicians who want to further their expertise in disorders of fluency. It is an excellent initiative, drawing in around 40 clinicians each year – mostly from Europe but this year as far afield as the Middle East and North America. Students' ECSF training is built around their regular clinical schedules and when qualified they receive a diploma. The students presented poster findings from their projects at the symposium and the standard was very high. For me, personally, it was a great opportunity to meet with colleagues and clinicians and to share information.

I was given a further opportunity following an invitation to talk to Danish SLTs at Castbergard in September, where I presented on both stammering and cluttering. Again, it was wonderful to learn from others' experiences and to find out how SLT services are run in other countries. Whilst there is no shortage of clinical expertise, there is a shortage of funding and specialist service provision. Sounds frustratingly familiar.

## Management

And finally, it seems no report of mine would be complete without mention of the latest game of musical managerial chairs to affect the stammer service. The latest managerial re-shuffle has brought in Sylvie Thorn as Head of Adult SLT services. I met with her last week for a long 1:1 and was very pleased that she seemed very interested in, and supportive of, the service. She was also impressed by the work of the Stammer Trust and will be visiting the apple house over the next few weeks to see first-hand the input that you have had in making it the wonderful place it is in which to work on fluency. I look forward to working with her to ensure the continued smooth running of the service.

As ever, my grateful thanks for the wonderful support of the Stammer Trust. Your work is very much appreciated.

**David Ward**

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## FUNDRAISING

Capt Jack Horner (aged 46) recently donned his training shoes and took part in the gruelling Race to the Stones, 100kms Ultramarathon in July of this year. The event took place along the oldest footpath in Britain 'The Ridgeway' which runs from Watlington in Oxfordshire, crosses the Chilterns to the North Wessex Downs, finishing at the Stone Circles at Avebury. As a former student of the Apple House, Jack volunteered to complete this challenge in aid of the Stammer Trust Charity and as a result raised £400.00.

Jack has stammered since he was a child. He joined the Army when he was 16 and has enjoyed a full career progressing through the ranks from Private Soldier to Warrant Officer Class One until he commissioned some 5 years ago. Jack continues to serve in the Army and help other soldiers with speech impediments.

*Jack said "the event was tough, one of the hardest challenges I have taken part in to date, but worth it – I have always stammered since I can remember and to be able to put something back in the system to help others means a lot to me, thank you"*



# GRANT AWARD UPDATE

## Fitbit for PWS: Respira R&D project Status (Successes and Failures)

### What are we building?

My name is Jordi and in 2016, I had the idea of creating a device to monitor breathing, speech patterns, and to provide real-time feedback and performance history tracking to assist PWS in out-of-the-clinic scenarios. I called this Respira ([www.respira.io](http://www.respira.io)), which means 'breathing' in Spanish. This is what we have achieved so far:

- Sept 2016 - Idea and team created
- Dec. 2016 – Terence Barry Grant awarded from the Stammer Trust (ST)
- August. 2017 - InnovateUK Grant awarded
- Dec. 2017 – R&D Project starts
- Nov. 2018 – Minimum Viable Product (MPV) completed (hopefully)

Although we are progressing each day towards our short-term goal - to complete and test our MVP - the development of an R&D project and the search for financial support is never easy. Nevertheless, as typically happens, the personal journey and the learning process turn out to be more rewarding than the goal itself. I have learnt more about stammering and myself in the last two years than ever before.

### Personal Journey (and Re-discovery of Stammering)

Up to the age of 30 I saw many SLTs, but unfortunately their approaches never worked for me. I usually stopped their support before summer holidays and avoided their calls after summer. Roughly every four years I would search for another new SLT in the hope to find the 'magic fluency key'.

Then at 34, I attended the McGuire Program and it really worked for me... for some time. My ability to say what I wanted without a struggle was not permanent, but sometimes it lasted weeks, which was amazing. I therefore attended many of their courses during the next two years. I realised that my success was due to the amount of training I was getting in out-of-the-clinic scenarios, with the help of other PWS who reminded me to be disciplined.

I thought, why can't we create a virtual speech coach who would remind me 24/7 to be disciplined? Besides, the device would monitor a number of physiological aspects of my speech that other PWS/SLTs could not monitor visually. I would therefore be more aware of all the small components and behaviours that I do not perform adequately in speaking situations. The idea of Respira was born.

My initial plan was to partner with the McGuire Program, as I was extremely grateful to them and I believed that the combination of intensive weekend programs + post-program continuous monitoring would work perfectly. But David McGuire did not support the idea and banned me from using his programme for my research. This was quite frustrating, but it turned out to be the best outcome possible: I was forced to explore the world.

I learnt that there are only a handful of techniques for PWS to gain fluency, but different countries, programs, schools, and SLTs called them in different ways. Therefore, I realised that the techniques taught by the McGuire Program were not too different from those taught by traditional SLTs. However, the McGuire Program has two additional components: 1) the out-of-the-clinic training and 2) emotional support group. The former could be integrated with Respira, but how about the latter?

## **Emotional Support Groups**

I attended the 2018 Cardiff BSA conference in September. It was an exceptional experience, full of workshops and keynote speeches. However, the most powerful experiences came to me from the group discussions I had with other PWS (similar to the McGuire Program). There are studies that correlate the overall feeling of happiness of PWS with the amount of time that they spend with other PWS.

We need to share how we feel with other PWS to improve and know more about ourselves. This idea is not new, since Alcoholic Anonymous (AA) have been doing something similar for 80 years. I think I had many similarities with AA individuals, because I was in denial and too ashamed of my stammer. I was brilliant at spotting a mile away anything related to stammering (including other PWS) and running away, as I did not know how to deal with stammering.

The combination of SLT techniques, out-of-the-clinic training and emotional support groups for PWS (Stammering Anonymous?) is what I believe to be the solution to improve the wellbeing of any PWS.

## **Lack of Public Support for Adult PWS**

We posted an article on the BSA website, Ref. [1], to recruit participants to run a study in combination with the ST and University of Reading (UoR), and have subsequently received around ten emails a month from PWS around the world. Many of those say that they do not have help available where they live. We are very fortunate to live in the UK, where support is more accessible than in other places. However, as discussed in the Bercow Ten Years On Report, Ref. [2], there is clear evidence of a lack of professional SLTs in some areas of the UK (private and NHS support).

I feel that there are more resources invested (from the government and businesses) for children than adults who stammer. Although this strategy makes sense, there are about 650,000 adults who stammer in the UK, and I have not seen any paper demonstrating that the early intervention in children who stammer 'cures' subsequent stammering in adults (please let me know if you find one).

For this reason, and in line with The Stammer Trust mission, we aim to "support the treatment of stammering, and research of stammering", by building a system that helps young and adult PWS around the world, irrespective of their location and financial situation. We expect to leverage technology and the data gathered to reduce the required amount of SLT involvement for each patient (to the bare minimum).

## **Financial Support Status**

Similar to the lack of funding in the NHS, and although we have the support of the leading charities linked with Stammering in the UK (The ST, BSA and AnxietyUK), we are struggling to find further public funding.

Also, dealing with InnovateUK (the organisation supporting Research and Innovation in the UK) has not been a straightforward process, as most of their protocols are not well defined, making the process to apply for grants unclear and quite frustrating.

Since we were unsuccessful on most of the grant applications (we also tried to obtain funding from Dominic Barker Trust), we have started to consider to look for private funding.

## **Project R&D Status**

Although there are a number of techniques to gain fluency, we found from interviewing SLTs around the world, that speaking sufficiently slowly and with enough air are the most important. While these techniques alone may not be a full solution for fluency, they are undoubtedly the basic requirement for any other fluency techniques or mindset to work.

Our initial prototype is working well enough with the above mentioned basic features, but it is still connected to a computer. We need to improve the algorithms further to be able to test it in the 'real world' (hopefully by Christmas 2018).

## **Conclusion**

We are incredibly grateful for the support we have had from the ST so far, who were the first ones to believe in us by offering the Terence Barry Grant Award. The ST also provided critical information on the current state of the art of similar previous developments. Special thanks to David Ward from the UoR for his patience and hard work as an advisor, and for help in writing grants.

I am utterly confident that the project will succeed, because I have faith in the saying "Do well by doing good" and in our hard-working team. If you would like to join us (in any capacity), please send me an email to [jordi@respira.io](mailto:jordi@respira.io). We are currently looking for investors, accountants, marketers, designers and software developers.

Best wishes,

Jordi

*If you want to increase your success rate, double your failure rate. (Thomas J. Watson)*

1. [www.stammering.org/speaking-out/article/respira-digital-coach-breathing-techniques](http://www.stammering.org/speaking-out/article/respira-digital-coach-breathing-techniques)
2. [www.bercow10yearson.com](http://www.bercow10yearson.com)

## ***RANDOM THOUGHTS ON STAMMERING***

In common with many people, I started stammering at an early age and found it very debilitating. I stammered through school, university and work.

About 25 years ago, I attended two intensive courses at the Apple House and have obtained a relatively high level of fluency as a consequence. That doesn't mean that I am perfectly fluent, but perhaps more importantly, I am very comfortable with where I am and the techniques I use to control my speech.

The courses were a wonderful grounding and taught me what I had to do to attain a level of control over my speech. Following the courses, I dedicated myself to practicing the techniques on a daily basis for at least a year. I don't do that anymore, but do practice when I make phone calls or am under some pressure. I've written before about breathing and techniques such as slow prolonged speech with soft contacts on hard letters such as a 'B' and 'D' and don't plan to reiterate here.

I am very keen on the techniques I have used successfully over many years (and still do) and these go hand in hand with other thoughts which I hope will help you. As I am an engineer, I make no apology for writing the list below:

1. I realised that I had suffered with severe blocks in the most awful situations and on the phone. I must admit that I felt acutely embarrassed as this happened frequently over many years. Then I realised that worrying about it only made it worse, so why worry? I had been in every embarrassing situation with my speech and I forced myself to accept this as it had happened so many times, it couldn't get any worse. So, accepting this was perhaps the start of accepting it which is very important. It didn't fix it, but it made me more comfortable with it.

2. Learning to talk about the stammer was very helpful, it got rid of the stigma to some extent and I found that people were genuinely interested. When my speech improved, my friends were interested to know how I had achieved the improvement. However, saying that, I'm sure that my friends would still be friends whether I stammered or not.

3. Listening to great orators such as Obama, Churchill (who had a stammer) proved to me that you do not have to speak quickly to be a great orator – the opposite in fact. Speaking slowly may not be a fix by itself, but it does help relaxation and allows time for breathing (something stammers are not good at).

4. I attended lots of meetings in a previous job and soon learnt that those who say the most are not often the ones who have anything interesting to say, the opposite in fact. Making succinct points are often those that carry the most weight.

5. Accept that stammering does not follow logic. The causes of stammering are many and complex, for example why can we sing ok and are often much more fluent when speaking to close friends and family. As I have a scientific background I really struggled with this – just accept that it is not logical and get on with it.

6. There has been much discussion on word avoidance and substitution. I'm not sure what the current thinking is, but my own view is that if it helps, do it and don't feel guilty about it.

7. When meeting someone new, try to break the ice with something which you find easy such as saying Hi rather than hello (I find Hi much easier to say than hello). Once you have started it makes the rest much easier.

I am not a speech therapist and urge you all to follow any guidance given or contact a therapist if you haven't already done so.

I hope some of these thoughts help somewhat, however, what is really important is that you accept where you are and work on methods which you find helpful.

**Ray Williams**

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## ***FLUENCY IN THE WORKPLACE***

### **An Obsession With Fluency In The Workplace Creates Barriers For Those Of Us Who Stammer**

Today is International Stammering Awareness Day - and I want to invite you to talk about talking at work.

If like 99% of the population you are a person who doesn't stammer, think about the last time you went for a job interview, presented to a client, or tried to win over a colleague about a good idea. My guess is that talking fluently and sounding right for the job was almost as important at winning your listener over as the content of your words.

In many businesses, respect, credibility and promotions are often awarded to the most articulate rather than those with the best ideas. In contrast, stammering - or stuttering as it's also called- is often regarded as a problem to be fixed rather than a difference to be accepted.

And for the 1% of the population who, like me, live with a stammer, this

presents a serious problem, even though research shows that people who stammer often possess above average skills in listening, creativity and empathy - highly #valuable skills to most employers and customers.

As Co-Chair of the Employers Stammering Network (ESN), people often tell me that their employers' expectation of fluency stops them from trying to speak in groups at work, fearing that they won't be taken seriously; fearing that their stammer will make them a figure of fun. So, they withhold their great ideas and become fringe contributors, losing out on development opportunities and falling behind.

Stammering is a complex neurological condition where the audible speech dysfluency is just a small part of the issue. Stammering, even as simple as not being able to say one's name, causes feelings of anxiety, shame and self-stigma. However, with an accepting culture and colleagues, these negative feelings can be exchanged for positive energy, full contributions and great outcomes.

That's why at EY we've just run an ambitious campaign headlining "It's OK to Stammer at EY" in the run up to International Stammering Awareness Day. We've been thrilled by the universally positive response!

The ESN has one core objective: changing employment culture so that everyone who stammers can achieve their full career potential. We want employers and employees to feel - to know - that it's OK to stammer at work.

To meet this objective, two key things need to happen.

Firstly, employers, managers and employees must find the courage to be open to having an honest conversation about stammering at work, and the role that the 'fluency over content' culture is likely to be playing.

But this isn't easy. Employees with interiorised stammers, whose speech typically sounds fluent on the outside, find it so difficult to reveal their hidden dysfluency while colleagues can find talking about stammering awkward and embarrassing. It requires the public commitment of the leadership, the encouragement of role-models and courageous conversations that ask for and explain how to achieve that change. Once engaged in conversation, people are often eager to learn and keen to do whatever it takes to accommodate colleagues with a stammer.

Initiatives such as Caroline Casey's #valuable campaign are critical to getting employers to create workplace cultures that embrace difference, and make it easier for those with a stammer to simply be themselves and build great careers.

#valuable calls on businesses across the world to recognise the value of the one billion people living with a disability and urges businesses to come forward to sign a commitment to putting disability on their board agendas by the end of next year.

Fundamentally, what #valuable is trying to do is to encourage more conversation in business about disability. The more we talk about it - in board rooms, and socially, by the water cooler, at after work gatherings - the more disability will become normalised. When that happens millions more people around the world will be reaching their career potential.

In the UK, it's estimated that if the gap in employment levels between people with and without disabilities could be halved, then the gains in productivity alone would benefit the economy by over £50 billion per year. Additionally, the wages and salaries earned would help to reduce income inequality and provide the social and health benefits of being in work.

On International Stammering Awareness Day, I encourage everyone to be open to entering into courageous and vulnerable conversations about stammering - and disability more broadly. Within work and outside, we need courageous leaders to drive forward the necessary cultural changes that will make it OK to stammer at work. Why wouldn't it be?

## **Iain Wilkie**

*Founder and Co-Chairman of Employers Stammering Network.*

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