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The Stammerer Trust

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NEWSLETTER



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EDITORIAL

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EDITOR'S NOTE



Welcome to our Spring newsletter.

The question "Is a stammer a disability?" often comes to the fore. The Equality Act (2010) defines anti-discrimination rights in respect of employment, services and education. A stammer would be covered if it affects one's ability to carry out normal everyday activities such as using the telephone or holding conversation. I have never regarded my stammer as a disability although sometimes have felt debilitated.

Recently I was struggling giving my surname when placing an order for an Indian takeaway over the telephone (my bugbear) which resulted in several silent pauses and 'hello, hello, are you still there?' while I battled through the plosives! My wife suggested I gave my Christian name or another name to make it easier on myself. I could but I would rather exercise those techniques I have learned to pronounce 'Barnes' without stammering.

In this newsletter we read the thoughts from two of our committee members. Rowan, our youngest recruit, gives an insight into his stammer within the classroom while Ray, our esteemed ex-chair, looks at ways to improve your fluency. At the AGM last November the Trust awarded small grants in the Terence Barry Grants Awards scheme. I am pleased to publish two reports from the award recipients: Mary Smith from Hertfordshire NHS Trust who was able to purchase some books to aid Parent Child Interaction Therapy sessions and from Jordi Fernandez who is developing a product, Respira, to monitor breathing patterns. They are launching a crowd funding campaign later this month to develop the product.

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 before 15th September.

Happy reading.

Andrew Barnes

Find us on Facebook: www.facebook.com/StammerTrust

FOREWORD FROM THE CHAIR



Welcome to another newsletter.

The cold dark nights are behind us, while plants and nature's creatures are all getting excited in the warm sunlight.

I am pleased to announce that the Border Morris group, Armaleggan, have made us their charity for the 2016/17 season. Wherever they dance they will be raising funds for the Stammer Trust. Unlike Cotswold Morris dancers, who wear white and have bells around their legs, Border Morris dancers wear darker clothes, bright coloured tatters, face paints and top hats. Fun, energetic and colourful. Check out their website, see where they are dancing and go see them in action.

We have provided Armaleggan with collection box wraps and business card style donation cards (the cards thank people for their donation on the front & have info about the Stammer Trust and website on the back). Likewise, any members wishing to publicise the Stammer Trust either individually or at events, we can supply a letterhead template, collection box wraps, sponsorship forms and Stammer Trust business style cards. Please contact Andrew or myself.

This year's applicants for the BSc and MSc speech and language therapy degree courses at University of Reading have again benefitted from volunteers who have assisted with the interviews, and chatted with the candidates during interview days. Further involvement meeting

current students and assistance with a number of degree modules continues to ensure that therapists trained at Reading will complete their courses fully equipped to credit their profession.

The highly respected Oxford Dysfluency Conference takes every three years, and will be held in Oxford in September. The Stammer Trust encourage therapists to attend, both to publicise research arising out of the work at the Apple House, but also for therapists to learn new ideas to benefit their patients.

Our Fun afternoon will be held at the Apple House on Sunday 25th June starting at 14:00. There will be activities, tea and a chance to meet each other. You are all welcome to attend.

Andy McCabe



THERAPISTS REPORT

Children's report to the Stammer Trust

The Children's Service at the Apple House has remained busy. Referral numbers are steady, although interestingly over recent months we have had an increase in referrals from teenagers, several of them girls, to whom we have been offering 1:1 therapy.

In 2016 the total number of referrals to the Apple House was 44; with 38 being school-aged children and 6 being pre-schoolers. This compares with a total of 53 referrals in 2015, with 41 being school-aged children and 12 being pre-schoolers. Of the pre-schoolers we have seen at the Apple House most have been successfully treated with Lidcombe Programme therapy and feedback from parents has been very encouraging. Emma and I continue to hold Lidcombe Link meeting at least twice a year with our community colleagues to offer support and update everyone's skills.

The intensive groups for 8-12 year olds have continued to be well-attended. Children's feedback from the summer group last year was very positive. Comments included: 'I made new friends and I enjoyed myself very much' (JB, age 10); 'I have learnt techniques to help me' (GW, age 12). Parents' responses included: 'Overall we feel DH has made good progress', and 'Our son seems totally unperturbed by the whole thing and absolutely loved coming to the group.'

The Intensive group this Easter will be slightly different in that it will comprise four children of older primary age – 11 and 12 year olds – and will run for three and a half days. This is in response to demand, and also staffing. The summer intensive group will be for younger primary aged children, 9 and 10 year olds. The Smoothies group, for 6 to 8 year olds will be run this May half term. There were an insufficient number of referrals to run the group in February half term.

Emma and I were delighted to be able to attend

the two-day training course in Palin Parent-Child Interaction Therapy (Palin PCI) held in January at the Michael Palin Centre. Our attendance was generously funded by the Stammer Trust for which we are both immensely grateful. I have written separately on our experiences of the training which appears below.

Finally, it is lovely to have the new working water heaters and the repaired storage heaters. Thank you to the Stammer Trust for its ongoing support and commitment to the Children's Service. Parents and children comment regularly on the specialness of the building and the support which they receive here.

Rachel Kennell

Highly Specialist Speech & Language Therapist
Clinical Lead for Dysfluency

18th March 2017

Report on PCI training course below:-



*Parent-Child Interaction Therapy training
Michael Palin Centre, London*

On 25th and 26th January, Emma Gough and I attended a two-day training course on Palin Parent-Child Interaction Therapy (Palin PCI) for children under seven who stammer. The training was held at the Michael Palin Centre in London and our attendance was very generously funded by the Stammer Trust, for which Emma and I are extremely grateful.

Palin PCI has been developed and adapted over a number of years. The theoretical model underlying the therapy approach is that stammering is a multifactorial disorder, comprising physiological, linguistic, psychological and environmental factors. Children are born with an underlying predisposition to stammer, but a combination of intrinsic and extrinsic factors contributes to the onset, development and impact of the disorder. Palin PCI aims to empower parents to manage their child's stammering, to develop their own skills in doing this, and to increase the child's fluency. Palin PCI is flexible and can be adapted to suit the

needs of each child and family. The first stage of Palin PCI is an indirect form of therapy i.e. parents and clinicians do not work directly on the child's speech. This first, indirect stage is believed to be effective for most children who stammer, although direct speech work may follow a period of indirect work, if necessary.

Emma and I were keen to attend this training for two reasons. Firstly, Palin PCI is a recognised therapy with a growing evidence base that is widely used to treat young children who stammer; however, it is one in which neither of us had been formally trained. As the specialist Dysfluency therapists for Oxfordshire we felt that this was a gap in our clinical skills which needed to be addressed. Secondly, before attending this training we were only able to offer Lidcombe Program to young children who stammer. We have had some excellent results with Lidcombe Program, which has a strong evidence base; however, we wished to have more than one therapy approach to offer families, particularly if we felt an indirect approach would be more appropriate, at least initially, or if, for whatever reason Lidcombe Program was not suitable.

Over the two day training we covered the theoretical basis for Palin PCI, assessment and therapy, and a review of the evidence base and the literature. Palin PCI incorporates a very thorough assessment, starting with an initial screening form. This determines whether the child can be discharged with advice at this point, or if a detailed assessment is required. A full assessment is undertaken if any responses to key questions on the initial screen identify that a child is vulnerable to a persistent stammer. Such 'warning bells' might be a strong family history, a stammer which has persisted for over a year, or which is getting worse, high parental anxiety or other speech and language difficulties. The focus of the full assessment is the child's profile of skills and how these affect their ability to be fluent within the context of the family. Carried out over two sessions it comprises a parent-child interaction video, a child assessment and a parent interview leading to a formulation (summary and analysis) and recommendations. The training stressed the importance of a thorough assessment which then guides therapy. Therapy focuses on parents' intuitive understanding of

their child and builds on this to facilitate the child's natural fluency. Watching the training videos (video is a major component of the therapy), the therapist asks the parent what they thought helped their child, and guides the parent to identify what they were already doing that was helping their child to be fluent. It was impressive to watch the clinician support, rather than direct, the parent and moving to see parents comment on their strengths and reach solutions together with the clinician. The tone of the therapy was very much one of collaboration between parent and therapist rather than direction by the clinician.

Palin PCI therapy has three main strands: interaction strategies, family strategies and child strategies. Interaction strategies include aspects such as following the child's lead, using more comments than questions, ensuring that the language used when speaking to the child is appropriate for their language level (for young children this will be using simple language), use of pauses etc. Family strategies include things such as Special Time, turn taking, being open about stammering and praise. Special Time is another key component of Palin PCI and is similar to Talk Time in Lidcombe Program. In Special Time each parent (and it must be each parent) spends five minutes with their child at least three times a week. The parent and child play together and the parent follows the interaction strategies outlined above. These strategies will be discussed and adapted at clinic sessions.

The format of therapy is a six-week block of therapy, with both parents and the child meeting with the clinician once a week for an hour, followed by a six-week consolidation period and then a review session. It was notable that the greatest change in fluency occurred during the consolidation period. Following the review session children are monitored for a least a year, or, if required, child strategies are introduced. These include direct work on speech rate (tortoise talking) and pausing (bus talking – you pause at the bus stops), and aeroplane talking (use of easy onsets – gliding into the word).

The training was very well delivered. The pace was excellent; there were practical exercises and lots of opportunities for discussion and reflection. The two days were very interactive. Emma and I came

away feeling enthused and informed and keen to put our new skills into action.

The training will have a direct impact on our ability to support young children who stammer and their families. The wider clinical skills that were also addressed will benefit all those whom we see at the Apple House and beyond. It is fantastic that

the Stammer Trust was able to support us in this training, to the benefit of all those with whom we work. Thank you.

Rachel Kennell

Highly Specialist Speech and Language Therapist and Clinical Lead for Dysfluency
The Apple House, Warneford Hospital, Oxford

The Only Person in the Class with a Stammer

You have a secret, which you want no one else to know about. You don't want anyone to know because you're the new kid that just wants to be like everyone else. That won't ever happen though.

Your life has been controlled ever since the Stammer came and sat on your shoulder. Unfortunately, none of us who Stammer have the power to rid ourselves of this nuisance. The Stammer is the devil on our shoulder.

I have had help from speech therapists over the years. They were good and supportive. Going to the Apple House, Stammer Trust HQ, was the best that my Mum discovered.

Roll on a few years. I'm in year six and in Primary School. Most people who stammer find their name the hardest word to say, I'm no different. In the register we had to say our names. I couldn't say it, nothing would come out. I struggled and struggled, but in the end the devil had won.

The next I knew, my Mum and I were on our way to the Starfish Project in East Sussex, a trip partly funded by the Stammer Trust. I have stammered since I was four years old. Both of us, especially me, wanted a change in my life. It all started from when my Mum called up Anne Blight, the founder of the Starfish Project and booked a place for me on the August course in 2010. I haven't looked back since.

Rowen Ellett



Some random thoughts on how to improve your stammer

Like many stammerers, I became aware of my stammer when I was about five years old. It began to seriously affect my life when I went to secondary school, University and finally when I started working.

I sought help in the late 1970's when I lived in Essex and latterly in the early 1980's with Gerda Wilson and other therapists at the Apple House who helped me build on what I had been taught in Essex. With a lot of dedication and help, I was able to get to a level of fluency which allowed me to control my stammer to such an extent that many of my friends and acquaintances are unaware of my previous problems. I have since spoken at many conference, chaired high level meetings etc. and

my speech has not been an issue.

In spite of being comparatively fluent for the last 30 years, I still consider myself a potential stammerer and rarely a day goes by that I do not apply the techniques I was taught all those years ago. I am not a speech therapist or clinician, but have applied the techniques that originated from such specialists. I will never forget how their help changed my life.

As I have a scientific background, I always found it hugely frustrating that I could not figure out why I stammered and why I could not simply fix it. In particular, I didn't understand why I could speak relatively fluently to my wife, but not to others. It probably all came to a head when I started work and found that I had lots of ideas and thoughts, but was unable to get them across. Don't get the impression that I had a few hesitation issues – I had massive blocks causing people to think we were cut off when on the phone etc. (sufferers will know what I mean).

The first course I attended in Essex, was 2 weeks, full time and very full on. I was introduced to slow, prolonged speech, relaxation, soft contacts and controlled breathing. I will go through each element and explain what it means to me. I know this technique has sometimes gone out of favour, but it works for me.

Slow

Like many stammerers I was very pleased to get on a run and spoke very fast to avoid stopping. This has two effects:

1. You run out of breath at sometime
2. When you do stop, panic sets in

On the course spent a lot of time speaking slowly, when I say slow, I mean very slow, starting at about 30 syllables a minute. Try it and see what it feels like.

Many stammers have a problem with this as it is so slow, it is also very hard to listen to, but also very relaxing. I took the view that going slow and only getting a few words out to start was better than having a block lasting a minute (I'm not joking). Speaking this slowly is not a fix in itself, but with the other techniques can form the basis of helping improve things.

One of (many) problems for me was answering the phone and getting something out before the caller put the phone down, thinking that there was no one there. All you have to do is say hello and so saying it slowly is better than saying nothing. Once you are over the start and feeling more comfortable, you can allow yourself to speed up a bit. I allow myself to speed up if things are going well, but am also prepared to slow down again if I feel uneasy.

Prolonged speech

Very simply this is running one word into another by continuing to voice the end of one word with the start of another. I use it particularly when I see a hard sound coming such as a B, I find it works very well. As far as I am aware, all stammerers are able to sing fluently, this may be one of the reasons why this is so.

Soft contacts

Hard letters such as B can produce glottal blocks as the lips come together firmly to make the sound and as many of you will know, this can cause problems. With practise, it is possible to say a B by only lightly touching the lips together and this makes it much easier. Similar techniques can be applied to other letters such as D (my favourite worse letter).

Relaxation

Obviously, this is very important and I guess most of us know the many techniques that can be employed. Relaxation in itself is not enough. In my case I could do a few minutes of relaxation and feel perfectly calm, the phone goes and it is all gone in an instant. It is important to learn relaxation, but by itself it is not enough.

Controlled breathing

As I indicated before, stammerers can speak very quickly when they are on a roll. This is ok until you run out of breath. Even fluent people would struggle to speak when they have no breath left, so better to get this sorted as it is one less issue to deal with. Many people (me included) breathe from their upper body and this tends to tighten up the shoulders and mouth which doesn't help. Learning to breathe from the diaphragm helps this. It is a technique used by actors and singers, so I suggest you Google or YouTube it. I use it, especially when the phone rings. Rather than grab the phone as soon as it rings, I start breathing in and then slowly pick up the phone. Just as the phone nears my ear, I start breathing out slowly and say 'hello' and sometimes add my name. Now I have got started all is well.

I myself have suffered with asthma and I know quite a few stammers who have the same thing. I believe that in some cases there is a link in that being short of breath makes speaking more difficult and this could then lead to a stammer developing as a consequence. I get asthmatic when I have a cold and I find I need to be ultra-careful with my speech at this time.

A few random thoughts in conclusion

- 1.** Don't think for a minute that this technique is easy. You can't simply have a go at it and the stammer will be fixed – it won't. Work on each element of it in turn and start to bring it slowly into your speech and conversations. In my case, it probably took me more than a year to get it something like right – but it was worth it.
- 2.** Don't be afraid to go slow, it is better than having a massive block or stumbling from one word to another and being completely out of control. Speaking slowly is a sign of authority, Winston Churchill used it to great effect. Remember that in an argument nothing upsets the opposition as much as you speaking slowly rather than ranting and raving!!!!!!!
- 3.** Practice going very slowly and see how relaxed you feel at say 25 words a minute. My worst nightmare was standing at a bar waiting to be served and all of a sudden, the barman is looking at you saying ... yes. Saying "a pint of lager very slowly" really doesn't take very long and is certainly better than getting stuck. 'A' is an easy letter to start on which is another advantage.
- 4.** It is not easy to accept a stammer, but you must learn to accept some level of disfluency, very few people are perfectly fluent, so accept it rather than let it get to you and make the situation worse.
- 5.** Accept that people who have never stammered, will have difficulty understanding the pain it causes and can say very hurtful things – they don't mean it.
- 6.** Many people think that 'having the gift of the gab' makes you a good conversationalist – it doesn't. Being able to listen and show an interest in what others are saying is the essence of conversation. Remember that we have two ears and one mouth – use them in that proportion.

I hope some of this helps in some small way. I can't end without thanking all the therapist who have imparted their knowledge to me and others and to the Apple House where I received much help. Also without the support of my wife and family, I would not be in such a good place.

Ray Williams

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 RCST 'Bulletin' and the BSA website. Six applications were awarded up to the maximum of £250

The successful applicants were:-

Pip Steers a Speech and Language Therapist from East Surrey Hospital - £149 towards a training course and purchase of books.

Mahmoud El Sherif a Psychology researcher studying at the University of Bath looking into links between stammering and dyslexia awarded £250 to assist in completion of work.

Mary Smith a Speech and Language Therapy, Hertfordshire Community NHS Trust awarded £240 to purchase eight books on childhood stammering.

Anna Prince a Speech and Language Therapist at East Trees Health Centre, Bath awarded £200 to attend courses: Acceptance & Commitment Therapy (ACT) and Solution Focused Brief Therapy

Jennifer Short a Speech and Language Therapist (Community Adult Service) awarded £250 to attend Acceptance & Commitment Therapy course.

Jordi Fernandez awarded £250 to help in the development of the product - Respira

Our first report is from Mary Smith

Stammer Trust Grant Award – THANK YOU!

Back in November 2016, the Children's Speech and Language Therapy Service at Hertfordshire Community NHS Trust were very pleased to receive a small grant towards resources for use with our stammering children.

The current service pathway for preschool children who stammer has a heavy focus on Parent Child Interaction (PCI) Therapy to support and empower families of young children who stammer. To further skill and embed this approach within the team, the grant from the Stammer Trust was used to purchase 8 of the Michael Palin Centre Books: 'Practical Intervention in Early Childhood Stammering'. Once the books were received, we were able to base a text in each locality team. The service ran 3 Bitesize Training sessions on PCI therapy and having the texts to hand enabled therapists to have quick access to the resources and theory needed to aid learning.

Follow the training, and consolidation of our Preschool Pathways, teams within each locality ran PCI therapy groups (called Smoothtalk) alongside 1:1 therapy where more appropriate for families. Again the text books purchased were invaluable for therapists running these groups helping them to support parents with underpinning reasoning behind the PCI approach as

well as providing families with resources and handouts which were printable from the discs that accompanied the text. Feedback from sessions ran with families was very positive.

Severity ratings for 2 families are outlined below:

Scale 1: On a scale of 0-7 where 0 is normal and 7 is very severe, how severe is your child's stammer?

Scale 2: On a scale of 0-7 where 0 is not at all worried and 7 is extremely worried, where are you now?

	Scale 1 (severity)		Scale 2 (worry)	
	Session 1	Session 5	Session 1	Session 5
Child: K	6	2	6	2
Child: F	5	2	6	3

Verbal feedback/comments included:

I found sessions useful and could see that the strategies were having a positive impact on F's fluency

I am aware of how to support J's fluency now based on the ST sessions

School reported that mum said that k's fluency was much better following sessions after Xmas

Thank you Stammer Trust for helping us make a difference!

Mary Smith

North Herts and Stevenage, Hertfordshire Community NHS Trust

Our second report is from Jordi and the team at Respira.

Title: Digital Coach for People Who Stammer (www.respira.io).

Summary: My name is Jordi. I am 39 years old and a person who stammers since I was 5. However, a few years ago, after attending a speech therapy program (the McGuire Program), I learnt new practices to be in control of my speech. Some of those practices are very simple but turning them into habits takes hard discipline and perseverance.

A few months ago, I realised how wearable



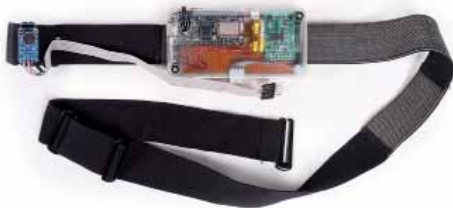
and Internet of things (IoT) devices are helping our daily life activities. As an engineer, I wondered if such technology could be used to remind us how to be more disciplined whenever good speaking habits are not implemented. Since then, I am working in Respira which brings some of

the techniques that I learnt in the McGuire Program into a wearable device.

Respira's innovation resides in its ability to monitor breathing patterns, speech speed and voice pitch, providing real-time feedback whenever good habits are not implemented. Therefore, it integrates techniques to improve fluency into an affordable wearable device that could improve the lives of people who stutter.

Respira also provides performance history to allow users to track their improvement. Finally, it records anonymous physiological data to generate a valuable pool of information that can be used by researchers to scientifically understand the mechanisms behind chronic stammering.

We have finished our first prototype and successfully tested it. Now we need to improve its performance as well as to miniaturise it. We estimate that the price of the final product would be around \$100 per unit.



The Stammer Trust greatly helped us by awarding to Respira a Grant to cover hardware development expenses and providing critical information on the current state of the art of similar previous developments. From the Stammer Trust Grant Award, about 80% was used in R&D and the rest was used to increase awareness of the project by building a landing page (www.respira.io).

The Stammer Trust also identified some systems (such as CAFET and Dr fluency)

developed in the late 1980s, which helped us to redefine our product. The two main features of our development are 'real-time' feedback and 'wearable' device (which makes it easy to use during daily activities). Implementing those key features into a device, at a reasonable price, was not possible 30 years ago (not even 5 years ago).



Next steps: The team behind Respira is composed of 3 scientists and 2 engineers. We are raising funding to work in the development of the final product, that we estimate, it will take one year. We are planning to launch a crowdfunding campaign in April 2017.

We would need your support by subscribing to our mailing list at www.respira.io. This will help us to launch our crowdfunding campaign. Also, we would appreciate if you could forward our project details to anybody that you thought could be interested.

Stammer Trust Grant Mission and Respira share the same goal: 'To support the treatment of stammering, and research of stammering'. We also believe that new technologies should be used to help people, like us, who stammer.

We would need your small contribution to help to bring this project to life. Thank you for your support.

Jordi and the Respira Team (Marcos, Dimitri, Rowan, James)

www.respira.io

Armaleggan, the Oxfordshire Border Morris group have named The Stammer Trust as their charity for the 2016/17 season.

Debbie Roberts, secretary, said "Your charity is particularly close to the hearts of some of our members: my husband, Mark Roberts and our Treasurer, Bev Baker, both attended courses at the Apple House many years ago when Gerda Wilson was with you. They both benefited greatly from the help and guidance they received and it would be lovely to put a little something back".

They publicise and collect at their dances, last year they raised a sum in excess of £2,500 for Oxfordshire charity, SeeSaw. Take a look at www.armaleggan.org for more information and see performance dates below.



Diary Dates 2017

29 April - Celebration of Spring with Grimspound Morris at Bovey Tracey (daytime)

1 May - May Day shenanigans

10 May - Tatters by the Thames – dancing at The Bounty, Bourne End (8pm)

20 May - Cuckoo's Nest 40th Birthday Day of Dance, Brighton

6 June - Cotswold capering – Pear Tree, Hook Norton (8pm)

14 June - Cheerful by the Cherwell – Victoria Arms, Oxford (8pm)

1 July - High-kicks by the Kennet – with Kennet Morris in Reading (daytime)

29 July - Getting our groove on at Wadstock Festival, Wootton and Dry Sandford

2 August - Dancing by the Downs – with Icknield Way in Wantage (8pm)

19 August - Tripping the dark fantastic at Tysoe Village Fete, Warwickshire