

ISSUE
117
Spring
2021

The Stammerer Trust

Charity Commission No. 265938

NEWSLETTER



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EDITORIAL

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PUBLICATIONS

The Stammer Trust
Newsletter is published twice
a year in April and October.
Suggestions for articles and
interviews for future editions
are welcome. Publication is at
the editor's discretion.
Copy deadline for Autumn
edition is 10th September 2021

WWW.STAMMERTRUST.CO.UK

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Kindly printed by
Multiflow Print Ltd
Tel: 01869 320200
multiflow.co.uk

EDITOR'S NOTE



Welcome to our Spring newsletter.

The pandemic has been a challenge for us all and have had to adjust to new ways of communicating. For some there has been less social interaction while others, working from home, spend their day in virtual meetings. Most people find wearing a mask (or face covering) uncomfortable which can also make communication more difficult for a stammerer. Like many, I struggle making myself heard and have the added dilemma of my glasses steaming up. A common problem for a stammerer is introducing themselves or saying their name, wearing a mask conceals my endeavour to say words with hard sounds or plosives. That said, I am drawing on exercises learned at the Apple House to help, so "I'll have a consonant please, Rachel!"

Stammering has been in the headlines over the past few months with Joe Biden becoming president of the USA and fellow stammerer, Felicity Baker, a BBC producer, recently stepping out in front of the camera for a documentary 'I Can't Say My Name: Stammering in the Spotlight'. Interviews with Michael Palin whose father had a stammer, former Welsh rugby player Mark Jones who put his reputation as 'dirty-player' down to his stammer and Big Heath a 20-year-old rapper who was bullied because of his stammer, as well as others made it a worthy watch. The documentary can be viewed on BBC iPlayer

www.bbc.co.uk/programmes/m000t27y

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 10th September 2021.

Happy reading.

Andrew Barnes

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FOREWORD FROM THE CHAIR



Thank you to all of you who attended our AGM held over the internet. For some it was the first time you had used this interesting mode of communication. I thank especially our speakers. Rachel described how the paediatric service has adapted and ran the first internet children's Apple House course. David reported on the challenges of the past year and the revised way in which he is working. Catherine Woolley gave an informative presentation of the play "Unspoken" which she produced for her MRes degree, the audience response to questionnaires and the audience Q & A. An active discussion followed.

The Stammer Trust has been less visibly active during the pandemic, however we have provided specific funding to the speech and language therapy service, continued publishing our newsletter, reviewed our costs and have moved onto internet banking. The therapists have been developing new skills, and are available to talk to people by phone, email or internet.

Those of us who for whatever reason, have been classified as clinically extremely vulnerable have faced restrictions rather more stringent than the rest of you. We therefore receive regular emails and letters from Matt Hancock, Secretary of State for Health and Social Care. They are not exactly very inspirational or motivational! Stay at home. Work from home. Do not go into work. Avoid shops. Send someone else to the pharmacy. Only exercise with caution. Although for our own benefit, the classification is also to prevent us overwhelming the NHS. We look forward to the end of such restrictions.

Finally I've been looking to the future. Wouldn't we all like to meet people rather than rely on Zoom, Skype, Facebook, phone calls and email? It will be interesting how we all choose to interact when restrictions are lifted. Will we treat groups of people more warily? Have a smaller circle of friends and contacts? Will we write more letters and send more cards? Will we want to travel to meet friends and relatives? How about air travel – airports, congestion, the expense and time that travel involves? How will we all choose to use our time? Possibly not the same as before the pandemic? Perhaps we have developed new hobbies or skills. I think it will take us all a long time to establish our new routines.

Look forward to meeting you all at our future meetings. June will probably still be by internet, whereas we hope the AGM in November can be held in person at the Apple House.

Take care

Andy McCabe

THERAPISTS REPORT

Children's Service report for the Stammer Trust

The Children's Service has continued to work digitally as the situation with Covid-19 persists. Referrals to the Service were much higher than usual during 2020: in December 2020 there were 18 children waiting for an initial assessment or second opinion at the Apple House, the highest number since I have been in post. The reason for this was a large backlog of children waiting to be seen in the wider team because of the pandemic (even though children who stammer are prioritised for assessment), and the impact of staff vacancies and maternity leaves. I think parents were possibly also more aware of, and anxious about, their children's talking as they spent more time at home during Lockdown. I am pleased to report that all these children have now been seen. Most of them are continuing to receive ongoing therapy with me.

Therapy has continued to be delivered digitally. As was touched on last November, there are advantages to this: it allows children to be seen at home or at school, which cuts down enormously on travel for both families and therapist. Appointments are generally easier to arrange and the disruption to families is minimized. For example, at Christmas I was able to fit in a block of Lidcombe sessions for a family who was re-locating to Durham in February at very short notice. There are also disadvantages: it is harder to demonstrate fluency strategies and therapy techniques to families over a screen, and interaction and the therapeutic relationship feel subtly different. Interestingly, younger children do not seem to be put off by working over a screen; some older children and teens have said it places them outside their comfort zone, but they have also said they find the sessions helpful given that they are currently doing so much school and college work over digital platforms.

The Stammer Trust very generously funded five sessions for me to support the work at the Apple House. I discussed this wonderful extra support thoroughly with my manager, Karen Fern, and we decided that the extra time should be used to develop the service in a way that would have a long-term impact on the work that we do for all children who stammer; therefore it was not used to see individual children on the caseload for therapy.

These extra sessions allowed me to look at our service model and contact colleagues in Swindon at the Fluency Trust to consider how they support children who stammer. I also prepared many digital resources for use by the Speech and Language Therapists in the wider team. These have been helpful during lockdown and can continue to be used to support therapy sessions when we are back doing more face-to-face work. Similarly, I updated and added to our range of advice leaflets. These now include links to video clips and websites such as STAMMA and the Michael Palin Centre. These resources have had excellent feedback from parents and schools and mean that appropriate advice is easily accessible and reaches families quickly. This does much to alleviate parental anxiety.

I have also delivered training and updates – again digitally – to my colleagues in the wider team. It has been hugely beneficial to the Children's Service to be able to do this work – so difficult to fit in while doing the 'day job' – and I am immensely grateful to the

Stammer Trust for their generosity.

Following the success of our first virtual therapy group last summer, a Smoothies group for children aged 7 to 9 years is planned for this Easter. This will run over three mornings, for an hour each morning. A group for older children aged 10 -13 will run during the summer. This may be digital, or face-to-face, depending on the situation with the pandemic.

As ever I remain enormously grateful to the support from the Stammer Trust: I may have spent less time physically at the Apple House in the past 12 months but the work of the Apple House has continued, developed and grown.

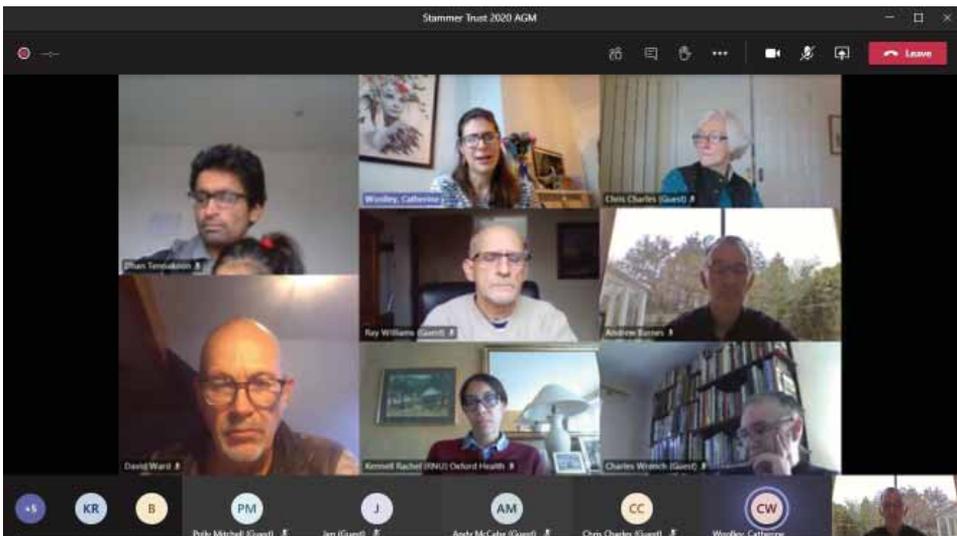
Rachel Kennell

*Highly Specialist Speech and Language Therapist and Clinical Lead for Dysfluency
Oxford Health NHS Foundation Trust*

March 2021

Virtual AGM 14th November 2020

Due to the pandemic our first 'virtual' AGM was held via MS Teams in the comfort of our homes. Those wishing to join received a link by email and could join us at anytime during the meeting. Attendees arrived in a virtual lobby before being admitted to the meeting by the administrator, David Ward. Armed with cups of tea and coffee, some with sandwiches, we soon got to grips with our new setting following some form of 'virtual' meeting protocol muting our microphones and raising hands to join in.



Our guest speaker was Catherine Woolley who presented the findings she produced for her MRes about people's perceptions of stammering when watching the stage play "Unspoken" that was performed in Oxford (2019).

Rachel Kennell gave a report on the Children's Service which has continued to give support during the pandemic with online technology proving invaluable. It was noted that many of the children had improved fluency at home while the parents noticed the stammer more.



Our first virtual AGM went well and was very productive with the added benefit that some members did not have to travel great distances. There were seventeen attendees including some former course members. While the next committee meeting will be held virtually we are looking forward to the possibility of a face-to-face AGM at the Apple House.

Future meeting dates are :-

Committee Meeting
Sunday 6th June 2021 at 12:00 noon (virtual via MS Teams)

Annual General Meeting
Saturday 13th November 2021 at 12:00 noon

STAMMERING MAKES THE HEADLINES

Stammering and Stuttering has certainly received its fair share of publicity over the past few months, most notably with Joe Biden being sworn in as the 46th President of the United States. He certainly isn't the first high profile politician to have had a stammer with Winston Churchill, Theodore Roosevelt and more recently Ed Balls, and not forgetting world leaders Claudius (roman emperor), King Charles I and King George VI on the list.

Joe Biden's speech inspired people worldwide as he negotiated some of the pitfalls a stammerer endures. He is open about his stammer and attributes his fluency to the support he received from his mother as a child. He said of his stutter "I still occasionally when I find myself really tired, struggle with my stutter." We can all empathise with this. Speaking at a meeting last year he said "I didn't have professional help, but I had three

things going for me. First, I had a mother with a backbone like a ramrod and she'd go, 'Joe, look at me. Look at me, Joey. You're handsome, you're smart, you're a good athlete, Joey. Don't let this define you. Remember who you are. You can do it.' We all have different ways to deal with our stammer, for some, this attitude from a parent might not help but having support from our family and friends, and fellow 'Apple-Housers' goes a long way. With Joe Biden taking up the mantle of one of the world's most important leaders this can only help many stammerers to follow their dreams.



Stammering featured in *Bridgerton* one of the biggest shows to grace our television screens over Christmas. *Bridgerton* is an overstated, colourful costume drama with wealth,



lust and betrayal set in the racially integrated Regency era looking at the competitive world of debutantes being presented at court. Leading lady Daphne Bridgerton is introduced to Simon Basset, the handsome Duke of Hastings and best friend of her elder brother.

The couple enjoy each other's company but the Duke shows a certain reluctance to marry and is keen to maintain his bachelordom. His unwillingness becomes apparent when the viewer learns, after seeing flashbacks to his childhood that he was bullied by his father for having a stammer and sent away to be tutored under Lady Danbury and ignores his son's letters. On his father's deathbed Simon vows he would never sire an heir determined to end the Hastings line. Sorry, no more spoilers!

Apple Music 'saylists' to help with speech issues

"Saylists" are being launched on Apple Music to help young people with speech-sound disorders.

The project, from Warner Music, uses algorithms to find song lyrics that repeat challenging sounds. The 173 tracks chosen so far include Dua Lipa's Don't Start Now, Lizzo's Good As Hell and Right Here, Fatboy Slim's Right Now.

One in 12 children in the UK is believed to experience some form of speech-sound disorder (SSD). Royal College of Speech and Language Therapists chief executive Kamini Gadhok told BBC News: "We're always pleased to hear about innovative approaches that support speech-and-language therapists in their work. As with all new techniques and

tools, we recommend effective evaluation and monitoring of outcomes."

One of the most successful therapeutic strategies for children with SSD is repeating challenging sounds, such as: **ch, d, f, g, k, l, r, s, t** and **z**

And, using the algorithm, Apple Music analysed the lyrics of the 70 million tracks in its catalogue to choose those that repeated them most often.

Stammering affects about 1.5 million adults across the UK - but it remains unclear why many develop the condition.

'Therapeutic tool'

In a recent documentary, BBC producer Felicity Baker talked about living with the condition and spoke to some high-profile people with a stammer, including a rapper who found music helped.

US President Joe Biden has also spoken about how his stutter helped him empathise with others.

Speech-and-language therapist Anna Biavati-Smith, who worked with Warner Music and Rothco on the project, said: "Saylists provide a fun new way to practise the sounds I teach children, without feeling pressured or getting bored."

Warner Music chief executive Tony Harlow said: "Helping people express themselves is at the heart of what we do - and we hope that by creating a therapeutic tool that's as engaging and accessible as saylists, we can help anyone whose struggling with their speech."



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Respira LTD and University of Reading Research update

As many of you will know, in addition to my work as a fluency therapist at the Apple House, I work part time teaching speech therapy students and conducting research at the University of Reading. Over the last two years we have received grant funded research to test and develop a digital aid for people who stammer. Indeed, the Stammer Trust can be said to have been in from the start of this project when a few years ago Respira, the company we are working with, started off their research program with a Terrence Barry grant award from the Stammer Trust.

Below, Dr Ronan Miller, my colleague working with me on this project, and himself a

person who stammers, provides an update on our work – and as you will see, there is a request toward the end.

Over the last few years, we have presented regular updates from Jordi and the team at Respira, who have been developing technology to support people who stammer. Respira, alongside the University of Reading recently completed a project funded by a grant from Innovate UK. During this project, the company were able to develop and test a wearable device and mobile application as a therapy adjunct to the Camperdown Program, a therapy approach that focuses on developing smoother, less effortful speech. In a small research study, Respira and the University of Reading were able to include participants from a number of countries, including the UK, Egypt, Nigeria, the USA, Jamaica, Poland and India. Videoconference software was used to deliver the Camperdown Program to a total of 16 people who stammer.

Outcome measures assessing quality of life, anxiety, and speech fluency indicated that all the participants benefitted from the therapy programme. The insights gained during this project allowed Respira to further the development of their technology and in August 2020 the company were awarded another Innovate UK grant to continue their work in collaboration with the University of Reading.

Previously, Respira has been focused on developing a wearable device to track biometric information and a mobile application. This approach has now changed to focus solely upon a mobile app that can deliver therapy content and also provide feedback to users in regard to their speech. This change means Respira will focus on developing software rather than hardware, which allows the company to be more flexible and to achieve similar outcomes and potentially reach more people who want to support.

To expand their expertise in this area, Respira have made several changes to their staff, these include the collaboration of a leading data science engineer whose work has been key in the success of Skype and Microsoft Teams, and an experienced senior mobile app developer. Half of the Respira team is now made up of people who stammer and together they have developed the BeneTalk mobile app, which gives real-time feedback on the speed of a user's speech. This represents an important milestone for the company, who are now working to increase the functionality of the application to assist the self-management of stammering. Later in the year the University of Reading will carry out research to assess the effectiveness of the BeneTalk mobile app. If you are interested in participating in the beta testing of BeneTalk, or in the research study, please visit www.benetalk.com and subscribe to be notified of future updates.

David Ward and Ronan Miller

THROUGH THE ARCHIVES

The Stammer Trust became a registered charity in 1972 and some years later the first newsletter was published to it's members and supporters. Over the next few pages is a reproduction of the first issue highlighting the dedication and support of the Trust's members which continues to this day.

While the copy is a little faded it makes a worthy read.

T H E S T A M M E R T R U S T

NEWSLETTER

No. 1 - May, 1975

This number FREE

KEEPING IN TOUCH

This Newsletter is primarily for patients and past patients of the Warneford Speech Therapy Treatment. We want to keep you in touch with each other, and with developments at the Warneford and elsewhere. We also want to tell you about the Stammer Trust, and its efforts to further the treatment of stammering.

To start with, we hope to issue a Newsletter four times a year. Each number will have four pages, and two of those pages will be taken up with news - news about the progress of the treatment, and news about the fund-raising and other activities of the Trust. For the other two pages we shall rely largely on your contributions. The third page will be where readers can let us know about their news. Write and tell us about a change of address, a change of job, an engagement, or an addition to the family. Tell us, too, about problems encountered, or experiences which might be of interest to fellow-stammerers or ex-stammerers. We shall be delighted to hear from friends and relatives, or indeed anyone with a personal or professional interest in communication through speech. Page four will be devoted to a longer item - a letter, article, or review, not necessarily on a speech topic.

The success of this venture depends largely on your support, so please do not be bashful about your fluency on paper.

This number is not quite typical of what is to come. For one thing, it is free. For the next three issues that will appear in the course of the next twelve months, there will be a subscription rate of 45 pence. This charge is intended merely to cover the cost of duplication and postage. If you would like to subscribe, please complete and forward the slip on the back page.

For another thing, the title "Newsletter" is only provisional, and all suggestions for a better one will be gladly received. The editor's ideas were howled down, but yours may fare better.

THE TRUST: THE STORY SO FAR

The Warneford treatment is now over ten years old. Thanks largely to Mrs. Gerda Wilson, who has run it since 1966, it has become widely recognised as one of the most exciting and successful courses available to adult stammerers. The work has taken place within the framework of the National Health Service, and with the kind co-operation of the hospital authorities.

Yet, as many of us know, much remains to be done. Money has never been plentiful. Gerda had to work for two years without remuneration, and she is still only part-time and single-handed. The hospital provides beds when it can, but separate sleeping accommodation for course members is urgently needed.

Until recently the courses did not even have a room of their own to meet in, but that has now been remedied, through the initiative of some of the patients themselves. In the Spring of 1972 they formed an action group, and undertook the conversion of an old apple store in the Warneford grounds. The Apple House provides a first-class treatment room, with a kitchen, office, hall and cloakroom below.

From this beginning developed the Stammer Trust, a registered charity founded in May 1973. The Trustees are Councillor Arthur Conners (a former Lord Mayor of Oxford), Miss Catherine Renfrew (Principal of the College of Speech Therapists), Mr. Norman Smith (a retired hospital administrator), and Dr. Seymour Spencer, of the Warneford Hospital, who has been closely associated with the treatment project from its inception. The Committee of Management (the policy-making and administrative body of the Trust) is chaired by Mr. Bryan Wilson, and is composed largely of old patients. (For the names and addresses of the officers see the back page).

The objects of the Trust are wide-ranging. They extend not only to the promotion of the Warneford project, but also to the furtherance of research over the whole field of speech therapy, and the encouragement of better provision for the treatment of adult stammerers generally.

Our principal aim at present is a specific one - to provide an extension for the Apple House building. Our architect, Mr. Arthur Marsh, has drawn up plans that have already been adopted by the Committee, and we hope to have a description of them in our next issue.

In order to enable us to carry out this work we are very shortly going to make an appeal for a sum of approximately £75,000. A selective appeal will be made to certain interested individuals, companies and grant-making bodies; and a carefully designed brochure for this purpose has been prepared.

MORE NEWS FROM THE TRUST

A meeting of the Committee of Management was held at the Apple House on 22nd March, when the launching of the appeal was discussed. It was also decided to inaugurate this newsletter.

-oOo-

After many delays, Ticker-Boxes are soon to go into production. Nordis Industries (a Northamptonshire County Council Sheltered Workshop) is to manufacture a hundred boxes as a prototype run, to a Plessey design. A price of £10 has been mentioned.

-oOo-

There is to be a Speak-In at the Apple House on 10th May, along the lines of the one that was so successful in the Summer of 1973. The idea is to give a talk to a small audience on a subject of your choosing, without more than the briefest notes to prompt you, and to get your friends to sponsor you at so much per minute. If you would like to perform, or to attend on the day, please get in touch with Gerda (Armada House, Weston, Towcester, Northants., Telephone Blakesley (032 732) 358).

-oOo-

The next meeting of the Trust has been provisionally fixed for 31st May.

NEWS ABOUT THE TREATMENT

It is good to record that Gerda's hours have been increased, with the result that this year she will be able to take three two-week courses and three refresher weeks. There is still no provision, however, for the assistance of a second speech therapist. And there is a long and growing waiting list. In future at least half the patients accepted for courses must be referred from inside the Oxford Area Health Authority. Our prime responsibility at present is to those in the Oxford area, and there is a shortage of beds for patients from a distance.

-oOo-

A very successful and enthusiastic course was held at the end of January. Of the seven patients, four were local, but the others came from Bath, Birmingham and Cumbria. There were two architects, two undergraduates, an industrial worker, a policeman, and an electrical engineer.

-oOo-

Nine patients attended a refresher week, from 17th to 21st March. There were rather too many interruptions, but we had some interesting guests, among them Mr. Ronald Muirden, who gave us the benefit of a lifetime experience, first as a stammerer and then as a self-taught therapist. Much of what he had to say about breathing and voice production seemed not incompatible with Stammer Trust speech techniques.

-oOo-