

A brief introduction

As many of you will be aware, after 3 years of working with the NDA John Marcus has recently left to pursue other exciting opportunities. He will be missed by us all, including of course the Tinnitus Support Group, but I am sure you will join me in wishing him the very best in his new venture. The group will be continuing, and as the new co-ordinator I thought it would be good to introduce myself, so that you know who you are contacting in the future. In turn, I look forward to meeting and getting to know lots of you over the coming months.

My name is Christina Brailsford, and I have worked at the NDA for about 1½ years. Within the organisation, I run HUSH! Club (a social club for people with hearing loss) and also work alongside Stuart Alcock doing the charity's reception and administrative work. My background is in heritage education and community engagement, and within this my focus is on disabled access to heritage and culture. I find that this works well alongside co-ordinating groups at the NDA, as I both jobs involve getting to have lots of good conversations, getting to know what is important to individuals and then trying to find ways to improve peoples' quality and enjoyment of life. In preparation for our group sessions, I am working hard to increase my knowledge and understanding of tinnitus, and am looking forward to spending some time at the NNUH Audiology department at the start of June to help with this. I am qualified to Level 2 in BSL, and spend my free time volunteering with various community projects and attempting to grow things in my garden - a pastime in which my enthusiasm definitely outweighs my experience and success!

Report from the last TSG meeting

On Thursday 15th May, John Phillips (Consultant ENT Surgeon at the Norfolk and Norwich University Hospital) gave a wonderfully engaging and useful talk entitled 'Dispelling Myths about Tinnitus'. He opened by listing some of the common myths that are associated with tinnitus: that it is something only 'old men' get; that no one knows the cause of tinnitus; that nothing can be done to help; that people with tinnitus cannot enjoy wine and caffeine, and that there is no hope for the future if you experience tinnitus. Mr Phillips then took each statement in turn and set about dispelling the myths! There is no substitute for being at the meeting itself, but below is a brief summary of the main points used to refute each myth.

If you have any comments or questions regarding the Tinnitus Support Group, please contact:
Christina Brailsford, TSG Co-ordinator, NDA, 120 Thorpe Road, Norwich, NR1 1RT
Tel: 01603 404440, Email: tinnitus@norfolkdeaf.org.uk

Only 'old men' get tinnitus	Wrong! While it is true that tinnitus is often related to hearing loss, and this in turn is more prevalent in older people, tinnitus is not specifically age-related. 1/3 of hearing children and 2/3 of children with a hearing loss experience tinnitus, and about 40% of children with glue-ear will too.
No one knows the causes of tinnitus	Wrong! Through extensive research, it is now known that tinnitus is perceived and propagated in the brain. It may often be initially 'triggered' by a problem in the ear, but the on-going sounds are created by the brain. This can be proved by the fact that people with no hearing (and even people with no inner ear) can experience tinnitus.
There is nothing that can be done for tinnitus	Wrong! While there is no 'one cure' (in the same way there is no 'one cure' for cancer), there are lots of very good treatments, and tinnitus symptoms can be improved (and in some cases completely removed). Treatments include (but are not limited to): use of hearing aids; cochlear implants; middle ear surgery; cognitive behavioural therapy or tinnitus retraining therapy, and relaxation techniques.
People with tinnitus cannot enjoy wine or caffeine	There are mixed reports regarding the impact of alcohol on tinnitus, but interestingly, a study showed that not only did cutting out caffeine not improve symptoms, but that the withdrawal symptoms made tinnitus worse! Mr Phillips explained that if an individual felt either substance was having a negative effect on their tinnitus, it would make sense to trial avoiding it, but that it was certainly not a blanket rule.
There is no hope for the future if you have tinnitus	Wrong! Mr Phillips ended his talk by mentioning a few very exciting developments that are happening right here in Norwich. The NNUH is currently undertaking a drugs trial to see if a medication derived from ketamine (AM101) may be able to prevent patients with acute tinnitus developing a chronic version. There is also a plan for a drugs trial looking at Meniere's Disease in the future.

As I hope these few notes show, there are a lot of myths that can really have a negative impact on how we view living with tinnitus. One of the main aims of the TSG is to help sort 'fact from fiction' in this regard, and then to provide ways of learning to manage tinnitus in a positive and proactive way, which leads me neatly on to the next section of this newsletter...

How can the Tinnitus Support Group help you?

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Included with this newsletter is a short questionnaire. It is really important to us at the NDA to ensure that the TSG meets the needs of the group members to the best of our ability. For this reason, we would like to 'take stock' and see what is working well, and where we can make improvements. As well as practical matters such as the best days and times for meetings, we would like to hear your thoughts regarding how the group can best achieve its 5 key aims, for group members to:

- feel supported emotionally and practically
- be able to cope with their condition
- be informed of the most up to-date-developments in the field and how these can improve their lives
- be informed of the equipment available to help them with their condition
- be part of a social network

I would be really grateful to receive as many questionnaires back as possible by **Monday 30th June** so that I can reflect on the results when planning the group meetings. If you would prefer to talk to me in person, on the phone or by email, please feel free to do so. The best time to contact me at the NDA is on a weekday between 8:30-11:30am. All contact details are at the bottom of this newsletter.

Next TSG meeting

Our next meeting will be on Thursday 24th July, starting at 7pm. We will be welcoming Claire Gatenby, Chief Hearing Therapist at the Norfolk and Norwich University Hospital. Claire will be giving a talk entitled 'Tinnitus: Why, When and What we do'. I hope to see many of you for what promises to be a fascinating and helpful evening.

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