

# Cambs Tinnitus Support Group

No. 147

NEWSLETTER

June 2019

## SELF-HELP SESSION

This month, instead of our usual November slot, the group is hosting its annual self - help session, where we have the opportunity to share our thoughts about tinnitus with others in a relaxed and informal atmosphere. Rachel Knappet, Head of Adult Auditory Rehabilitation at Addenbrookes, and committee member, will help guide us through the session.

**Saturday 15 June**

**10.00 for 10.30 am**

## Meadows Community Centre

1 St Catherine's Road, Cambridge, CB4 3XJ, off  
the junction between King's Hedges and Arbury Rds

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Refreshments and Raffle

## EDITOR'S CHAT

Members who have been with the group for a while will be familiar with the layout this newsletter usually follows: interesting (hopefully) tinnitus research topics, no more than one page long, and other related items plus some jokes to promote a chuckle and lighten the mood. At our April meeting we were fortunate to hear Dr James Jackson talk to us about his latest tinnitus research, involving an aspect that was certainly new to me. I don't think we have ever had the opportunity to hear a researcher explain the rationale behind their work and then take us on the journey from developing an idea to following it through, via a study, to the results and conclusions. For those who were fortunate to be there, and over 30 of us were, then they will know what I mean. James spoke for 80 minutes, he sent me 107 slides, and my resultant notes ran to nearly 12 pages. One member even contacted me asking if there a DVD of the presentation - I wish there was, it would have saved me quite a lot of work! What you have is a just over 2 page report which I hope does justice to his talk and which I hope those people who missed it as will find as interesting as those who attended that day. I promise there are also some jokes for you to chuckle about - hopefully!

Those with e-mail will already be aware of the change to the published programme due to the untimely accident to Claire Gatenby who recently sustained a broken hip. I'm pleased to say that Claire will now be talking to us in November before our Bring & Share brunch, and June will now be our self-session, led again by our wonderful facilitator, Rachel. We hope to see you there.

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### Jim's Piece

As your chair, it is a privilege to serve such a supportive and engaged group. I always draw inspiration from our meetings which are informative and enjoyable social occasions, and I believe you do too – as shown by our excellent attendances. The committee does its best to create a welcoming and inclusive atmosphere which supports our good balance of newcomers and regular members. I'm very lucky to live only 5 minutes away on my bicycle (*although you are often one of the last to arrive!* - Ed), and we appreciate that some of you travel large distances to attend. We are very fortunate to have such interesting and motivating speakers who often come some distance - our last speaker came all the way from Brighouse, West Yorkshire, leaving home at 5.30 am! I hope our meetings continue to help you with your personal tinnitus journey, being able to share with those who face similar challenges and knowing you are not alone.

With best wishes  
Jim Infield

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### 2019 AGM SNIPPETS

Jim Infield, the CTSG Chair gave his usual report of the year's activities. As always, we have had some excellent meetings with a good balance of information and opportunity to exchange ideas. The value of our meetings was reflected in the attendance, which has averaged over 28, slightly up on last year, and is a good number that works well for group dynamics. Faradena (Fara) Afifi kicked us off in February with a demonstration of Tai Chi that was enjoyed by all, particularly as we got to go outside in the sun! We hope to see her back soon. In April Dr Kathryn Frackrell from the Nottingham HBRU came to talk to us about her Hyperacusis Project, and Jess Williams, from Addenbrookes outlined her research project. September saw Elinor Brown, from Growmindful, give us a really excellent insight into Mindfulness-Stress Reduction. We had hoped to organise a series of regular sessions with her, but unfortunately this did not come to fruition. November saw Rachel Knappett lead a very well attended self-help session, followed by our ever popular Bring & Share Brunch.

In April, Nic Wray, BTA Communications Manager and Editor of Quiet, gave us an in-depth report on the progress made over the past five years to answer the Top Ten tinnitus research questions resulting from the Tinnitus Priority Setting Partnership project.

Tinnitus Week 2019 in February saw Sue and Alan at Hinchingsbrooke Hospital for 2 days, although this was not as successful as in previous years. In contrast, Addenbrookes, with Janette and Alan, was its usual busy self. Our website and Facebook page are up there in the cloud for all the world to access, and we have had several contacts from the website.

Thanks to the committee for once again organising some excellent meetings, and a very special thanks to Alan for the newsletter and constant dedication and hard work behind the scenes. All the committee were willing to stand again this year.

One bonus to our funds was a surprise donation of £660 from the Chairman's charity of the Fenland District of the Oddfellows. We have yet to decide how we will spend it.

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### CHUCKLES I

- Artificial Intelligence is no match for Natural Stupidity
- Why is the time of day with the slowest traffic called 'rush hour?'
- What's the best way to kill a variety act? Go for the juggler. Boom Boom!
- An attractive girl walks into a fabric shop to buy some material for a dress. 'How much does it cost?' 'Only one kiss per metre,' replies the male clerk. 'Fine,' replies the girl. 'In that case I'll take ten metres.' The clerk gives her the fabric and the girl points to the old man standing next to her, 'Thanks,' she says, 'Grandpa's paying the bill.'

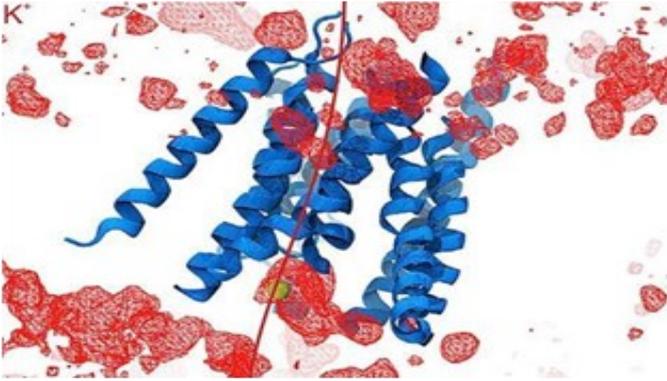
### Sound-sensing protein finally found after 35-year hunt

Summarised from article in *Neuron Issue 4. 08/2018*

*A 35-year quest to understand the fundamentals of hearing may finally be over, after scientists in the US identified key proteins in inner-ear hair cells that produce an electrical response to sound.*

A team of researchers led by David Corey and Jeffrey Holt at the Harvard Medical School says it has conclusive evidence that a protein known as TMC (transmembrane channel-like)1 forms the basis of hearing in vertebrates.

The Harvard team showed that TMC1 and closely related TMC2 proteins form sound-activated pores



Predicted architecture of the protein responsible for turning sound into electrical impulses that the brain can understand

through which positively charged ions flow into inner-ear hair cells. This establishes an electrical signal that is relayed to the brain via the eighth cranial nerve. To understand how the protein works, the research team first deduced its structure, and then investigated the roles of individual parts of the molecule.

Unusually among ion channel proteins, TMC1 forms a dimer (two identical units). By using cryo-electron microscopy and comparing their data with that from another pair-forming protein, TMEM16, the researchers were able to infer information about TMC1's structure.

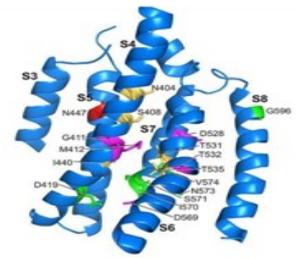
'The similarities were enough that we could guess what the TMC looked like and then to guess where within the TMC the ions would pass through to get to the inside of the cell,' explains Corey.

Having solved the structure of the TMC1 protein, the team set about assessing the role of individual amino acid groups within it. The researchers created 17 mutant TMC proteins, and then examined their activity when inserted into cells in live mice that had been genetically programmed to produce no natural TMC.

'Those changes altered the flow of current into an intact hair cell, and that told us then that the TMC was the pathway for this special sound-activated current flow into the cell,' says Corey.

Corey's team are now on gene therapy strategies to treat specific mutations in the TMC1 protein. However, he also notes that now TMC1's function has been identified, there is still much to learn about the way it works within a cell and how it interacts with the other proteins it connects to. He compares this to trying to unravel how the different parts of a clock mechanism work together.

He says, 'With the pieces in front of us, the really interesting challenge is to figure out what connects to what, what moves what, what makes the whole mechanism work. And that will keep us busy for another decade at least.'



Sites of the 17 mutations that were introduced to TMC1 to probe how it worked

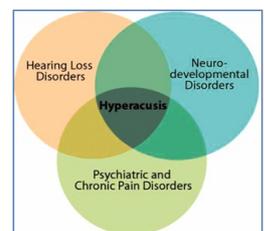
(A very short version of this article appeared in an earlier newsletter, this is the full Monty Ed)

### Physiological mechanisms of hyperacusis: an update

(Edited from NT & Audiology News article)

Hyperacusis is a debilitating hearing disorder that affects up to 10% of the general population, and advancing and treatment of hyperacusis requires a better understanding of its underlying neural mechanisms. This is complicated by the diversity in both its cause and clinical presentation. Recent efforts have been made to model distinct forms of hyperacusis in animals in order to help elucidate potential underlying mechanisms.

Hyperacusis encompasses a wide range of reactions to sound and, as such, its definition has been vague. From clinical presentation four subtypes have recently been identified based on: excessive loudness, annoyance, fear and pain. The condition is also often associated with hearing loss and tinnitus. Sound tolerance disturbances are observed, however, across a wide range of neurological disorders, including neurodevelopmental disorders like Williams syndrome and autism spectrum disorders (ASD), psychiatric disorders like depression and post-traumatic stress disorder (PTSD), as well as chronic pain disorders like migraine, and complex regional pain syndrome. Thus, hyperacusis is diverse in both its etiology (causation) and expression, and it is imperative to consider this diversity when attempting to define its physiological mechanisms.



### CHUCKLES II

- A salesman, tired of his job, gives it up and becomes a policeman. Several months later a friend asks him how he likes it. 'Well,' he replies. 'The pay is good and the hours aren't bad, but what I like best is that the customer is always wrong.'
- A lawyer walks into a client's cell on death row and says, 'I've got good news and bad news.' 'What's the bad news?' 'The bad news is that the Governor won't issue a stay of execution.' 'That's awful. What could possibly be the good news?' The lawyer replies, 'I managed to get your voltage reduced.'

Our speaker for this meeting was Dr James Jackson, a Chartered Psychologist from Leeds Trinity University. His doctorate considered the effects of tinnitus on concentration and task performance, while research interests included how tinnitus affects individuals, how personality affects tinnitus distress, and whether objective measurement of tinnitus is possible. Not surprisingly these areas of interest formed the central theme of his presentation.

Introduction

James started by explaining that he was a psychologist, not an audiologist, and it made a change not having to spend 10 minutes explaining to his audience what tinnitus was! He has had tinnitus all his life, and has also been deaf for many years, suffering a catastrophic hearing decline on entering university. During many resultant tests he realised for the first time that the noise that had been with him from birth was tinnitus, and an 'invader'. The next day his 'noise' was horrendous, and it took him 10 years to come to terms with it; and this experience was the main reason why tinnitus became the main focus of his research.

The 'loudness' of tinnitus

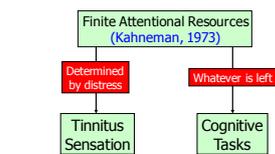
Early research found the perceived sound of tinnitus was extremely low (15 dB) compared to external noises, and more recent experiments has confirmed this. However when the researchers also asked the patient how distressing their tinnitus was on a scale of 1-10, they found about a third were 'moderate', but over 50% were 7+ or 'severe'. They thus concluded that the tinnitus was not a function of 'loudness'.

Perception & Attention Resource

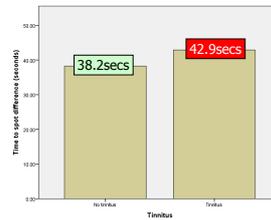
Tinnitus involves strong emotional and cognitive elements, which most see as upsetting but not threatening. The main issue is the constant presence and our inability to control it. Tinnitus can also involve concentration difficulties, but what does this mean? James began by giving patients some cognitive tests – the first being the Stroop test. James demonstrated with alternating slides showing Blue and Green and we had to call out the colour of the word. We hesitated fractionally over our answers, which is normal, but apparently those with tinnitus react slower, and the more distressing the tinnitus is, the people hesitate.

Classic psychology says humans only have finite attentional resources. We have evolved to detect a threat, so if our tinnitus is perceived as a threat, then we pay it more attention, leading to a feedback loop and a vicious circle. The focus of our attention is below our consciousness and we lack the ability to ignore it.

James explained that there is disagreement among researchers as test results may be affected by personality, differing skills etc. A 2014 study showed bothersome tinnitus was associated with higher neuroticism scores (a personality trait characterized by anxiety, lack of confidence etc.). As a result, these patients don't like being judged, or measured, which may explain why they do



less well in tests. Our speaker tried again to demonstrate this discrepancy in behaviour by using another cognitive test known as Change Blindness, where you have to differentiate between 2 flashing images and spot the difference asap. (A classic example that most people know is the video of the gorilla moving through a crowded room). From his trial James found the time difference between those with and without tinnitus was significant, reflecting the



fundamental limitations of human attention.

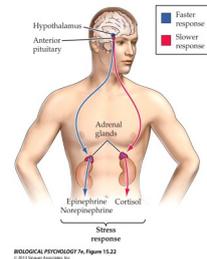
Cognitive tests not working out

James concluded that trying to gauge how distressing tinnitus is to someone by using their responses to cognitive tests was not giving consistent enough results. The usual way of measuring the effect of tinnitus on people is via questionnaires, however there is evidence that if patients are depressed about their condition then this may impact on their responses, and lead to misleading answers. This is very relevant to the current prevalence of major depression in the populace, which can be high for tinnitus patients. So is tinnitus causing depression or are people with depression more vulnerable to the condition? No-one really knows – we need a better measure of how people are coping with their tinnitus.

Measuring stress

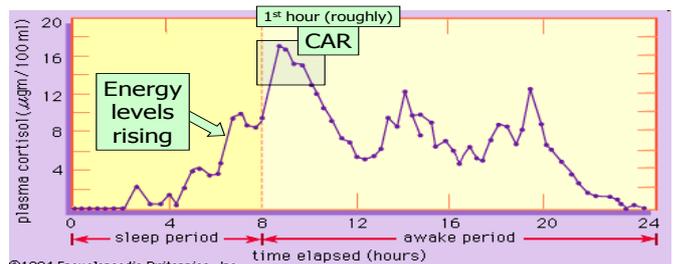
A famous quote by Wolfgang Linden say measuring stress is like measuring winter, and James is not keen on self-reporting questionnaires to measure responses. However gauging behaviour, along with physiological changes in the body - is a possibility. We cannot consciously control our autonomic (hormonal) system, and James decided to use this method, choosing cortisol as his hormone of choice. The adrenal gland is very important, as it produces Epinephrine (adrenaline) and cortisol (a glyco-corticoid). Cortisol comes from the metabolism of sugars which in turn gives us the energy for 'fight or flight', and also controls our appetite.

Figure 15.22 Stress Activates Two Hormonal Systems



Diurnal rhythm

The production of cortisol follows the body's diurnal rhythm, being at its lowest when we are asleep, and rapidly increasing



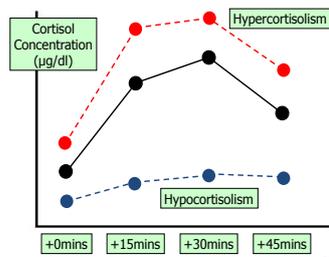
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 when we awaken, by helping drive the process. This is known as the Cortisol Awakening Response (CAR). The most stressful part of the day is within the first 45 minutes after we have woken, so if we measure the cortisol level in this period, it should give us a lot of personal information. But how do we measure it?  
Measuring Cortisol

We could measure cortisol in urine, but this would tell us more about what happened in the last 24 hours, rather than now. You could measure blood, but using syringes just after waking would be impractical. You could measure cortisol in hair, but you would need a sample 3 cm from the scalp, and it would mostly tell your cortisol history over the past 3 months, and not current levels. The best method is via saliva, which is much simpler to sample, and 70% of your saliva is secreted from under your tongue. So in your own home, you wake up, pop a synthetic swab under your tongue for 2 minutes, put the swab back in its container and then store it in the freezer. However, providing a sample straight after waking can be tricky, and if you need another 5 samples then you could run out of spit!

Cortisol profiles

Some people with anxiety-related symptoms, such as anorexia or OCD, produce too much cortisol (hypocortisolism), and patients who are tired, possibly depressed or in chronic pain, don't produce enough cortisol, known as (hypocortisolism). James thinks this a good diagnostic tool to judge if patients may have a particular problem.



Diagnostic Tool?

Research shows that ~75% of people have a normal CAR profile and ~25% have an abnormal one, which may indicate they may have a problem. James wondered if tinnitus could be one of those conditions which could affect 'normal' people. A large number of studies show that CAR only occurs after significant sleep (not after naps), because the amount of cortisol secreted depends on what is going to happen during the day. (i.e. situation awareness and future demands). Additionally, on awakening there is a significant increase in hippocampal activity (which controls memory), and this helps the body gauge how much cortisol is required for the day. This effect has been called the Anticipation Hypothesis.

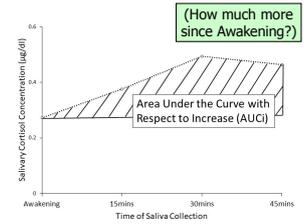
Link between Tinnitus and Cortisol

This has not been widely explored and most studies are inconclusive. If attacked by a tiger you want the spike of cortisol for 'flight', however you want to turn cortisol off again so you don't get over-stressed; this is one aspect of Blunted Stress Activity. People with tinnitus don't have this ability, so it takes longer for them to get stressed (secreting less cortisol) and the hormone hangs around longer than ideal - which is an unhelpful response.

Problems of measuring cortisol in a study

There are multiple ways of measuring cortisol, but James thinks only two are really important. From the basic graph over 45 mins, the area under the basic

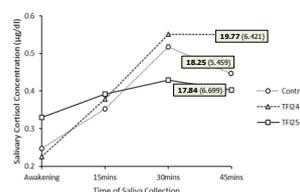
graph over 45 mins, the area under the curve (AUC) is the total cortisol secreted. However, if you compare this with how much cortisol has been secreted since waking (AUC with respect to increase - AUCi), it indicates your anticipated need for the day ahead. No-one had measured AUCi before, and James



surmised that people with severe tinnitus would produce less cortisol (Hypercortisolism), as shown by lower AUCi values, and as a measure of demand, AUCi will also effectively predict daily distress. With a small grant from the BTA, he was able to fund a small study with 30 participants – 20 with tinnitus, 10 without (controls), consisting of 18 men and 12 women.

Study and Results

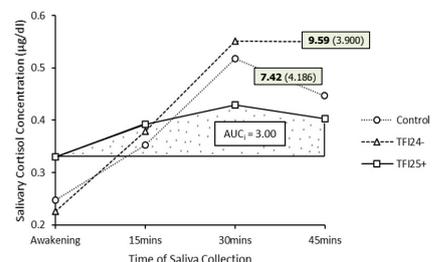
The usual protocols for this type of study were followed, so tinnitus distress was measured with the Tinnitus Function Index (TFI), with scores converted to 0-100. So levels of distress were TFI 24 (mild/habituated), TFI 25+ (significant) and TFI 50+ (severe). Saliva collected at awakening (0) and then at 15/30/45mins/+6 hours (lunch)/+12 hours (dinner) intervals. Of the 20 tinnitus patients, 9 coped well (TFI 0-24) and 11 (25+) not so well, which with the 10 controls, gave 3 almost equal groups. The control



group gave almost perfect profiles, and the TFI 24 group showed a similar profile to the controls i.e. a similar release of cortisol. The TFI 25+ group's baseline started lower than the others but their profile was still flatter than the other 2

groups. If you measure AUC, the 3 groups values are statistically similar, but if you measure AUCi, the profile of TFI 25+ shows a significant lessening of secreted cortisol – very similar to the profile of depressed people waking up and expecting it to be a hard day. The AUCi value

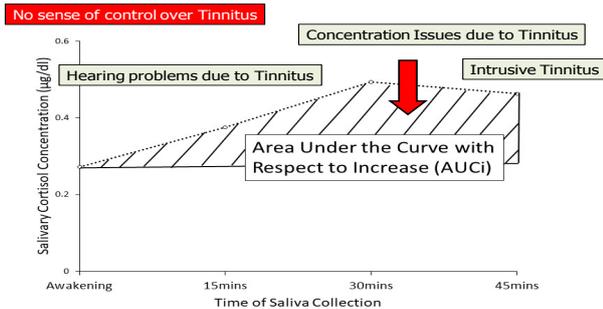
also has a strong relationship with that of people 12 hours after waking up (significant tinnitus stress),



AUCi shows less cortisol secreted from TFI +25 group

which may suggest that if you wake up with a positive frame of mind, things will feel better. The TFI breaks down into 8 subsets, and James says it appears there is a relationship between how flat your CAR profile is and various aspects of the index (e.g. intrusiveness, sense of control, concentration and auditory problems - see slide over page).

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With a flat curve, someone who wakes up and thinks the day ahead will be hard, then these aspects of tinnitus matter. This seems to be the key that can affect your well being, and in order to make people better, these are the aspects we need to deal with. If we improve these elements then a person's cortisol profile may rise and help people with tinnitus to become habituated.

## Conclusions

Using cortisol profiles we can identify the most distressed people with tinnitus and predict their challenges during the day. A recent study involving girls with anorexia (involving depression etc.) showed a good intervention brought down the amount of cortisol they secreted and helped cure their condition. Similarly, James thinks that CAR can be used to help those who are really struggling with their tinnitus, and could help indicate if an intervention had been successful or not.

To conclude, these findings need to be replicated because the inter-personal variability within CAR is high, so more testing is needed. Measuring AUCi is also not a very practical test and is out of reach of many audiologists (cost & challenge).

James's talk finished with a lively Q & A session, and very warm applause from our members. Having been up since 5.30 am to catch the train to Cambridge, he was taken to dinner by Rachel and Eldre before catching his train home.

## CHUCKLES III

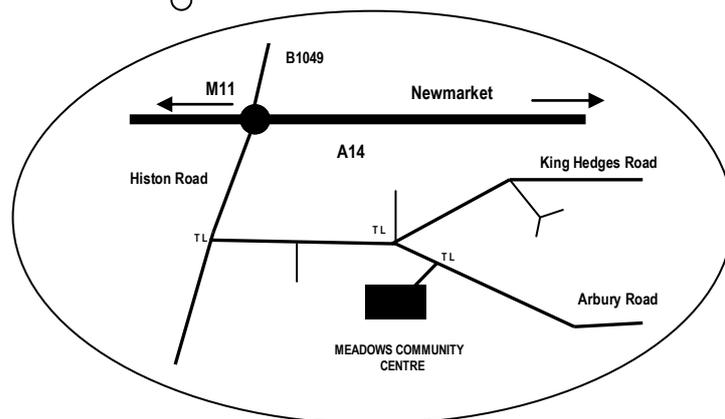
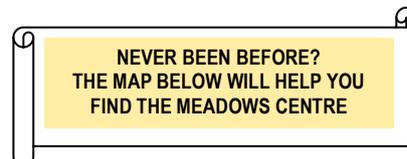
- A priest visits a man who is grieving over the death of his aged father. 'I'm so sorry to hear of your loss,' says the priest. 'Did you try taking him to Lourdes as I suggested?' 'Yes, we did,' replies the man. 'But we'd only been there a few minutes when he passed away.' 'Was it his heart?' asks the priest. 'No father,' replied the man. 'He got hit on the head by a cricket ball.'
- A cowboy comes out of a saloon and finds that someone has painted his horse with whitewash. He storms back inside and shouts, 'Which one of you idiots whitewashed my horse?' A huge gunslinger stands and says, 'Me. Why d'you want to know?' 'No reason,' says the cowboy. 'Just thought I'd let you know the first coat is dry.'

## Please remember

*This is your newsletter and all comments, letters, contributions or editorial copy relevant to tinnitus or CTSG, or anything you think maybe of interest to our members would be very welcome. Please send to :-*

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Facebook: **Cambs Tinnitus Support Group**



## CONNECTIONS

CTSG is an independent voluntary organisation with a good supporting relationship with the Audiology Department at Addenbrookes Hospital. It is also a BTA registered tinnitus support group. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting room, printing and postage of Newsletters, replacement equipment and associated activities.

Our next meeting is on Saturday 21st September at the Meadows Community Centre, when Laura Falco from the Ménière's Society will be our speaker.