ICH2 Newsletter

2nd International Conference on Hyperacusis
9-10 July 2015, Venue: Birkbeck College University of London
www.hyperacusisresearch.co.uk
Welcome to the first edition of ICH news! This year the second International Conference on Hyperacusis (ICH2) will be held on the 9-10th July 2015 at Birkbeck College, University of London and we are delighted to hold this event for the public as well as professionals.

The conference theme ‘Public Involvement in Promoting Hyperacusis Research and Clinical Practice’ promises to be on par with the successful and well attended conference in 2013. The conference aims are to (1) raise awareness about hyperacusis, (2) exchange ideas, experiences, and research outcomes on assessment and management strategies for hyperacusis, (3) discuss implications of findings from experimental studies for clinical practice, and (4) encourage involvement of patients in guiding research directions and clinical practice.

In the lead up we will be updating you with news relevant to hyperacusis plus interviews with experts, patients as well as news from around the world to help put research outcomes into perspective.

Subscribe for FREE by emailing us at admin@hyperacusisresearch.co.uk to get your online copy every 2 months from now until August 2015

Enjoy our first issue!

Hi, I’m Wei Sun. I am an associate professor in audiology at the State University of New York at Buffalo. I have been working on animal models on tinnitus and hyperacusis for several years. I studied the physiological changes in the auditory system correlated with animals’ behaviour. I enjoy reading and discussing questions with the physicians and patients through the ICH group. This makes me feel that my study is valuable. I believe everyone’s problem is different. But there must be something similar in different cases. Using animal model can help us to better understand these disorders. I enjoy working and love to play sports and spend time with my family.

Hi, I’m Natasha. I am an Audiologist who graduated with a BSc from the University of Bristol in 2011. Since then I have been part of a great team at Swindon's Great Western hospital, with tinnitus and hyperacusis as my areas of interest. By joining the ICH committee, I want to help build our knowledge of hyperacusis and encourage international communication in learning more about this condition. When I’m not talking about ears, I like to travel, eat cake and do photography.

Hi, I’m Safeeya. I am an Audiologist at Whittington Hospital in North London. I have a great interest in tinnitus and hyperacusis. Being part of the ICH2 team is exciting as there is much work to be done in this field. Current research has only scratched the surface, but hopefully together we can make our voices heard and help those affected. I enjoy the outdoors and love travelling and exploring the rolling English countryside. When I’m not outdoors you can usually find me curled up with my 3 cats.

Contents:

- Why public involvement? 3
- Living with hyperacusis 4
- Research Update 5
- Hyperacusis combined with tinnitus 5
- Animal experimental studies and hyperacusis 5
- Key outcomes of ICH1 2013 7
- Learning from OCD 8
- Call for abstracts 10
Why public involvement?

This year we want to get the public involved in ICH2, as well as professionals. Hashir Aazh, the Conference Organiser, discusses why this is important to us.

We do not fully understand the underlying mechanism of hyperacusis. In people who experience hyperacusis normally tolerable sounds are perceived as excessively loud, annoying or painful. Many people may not be familiar with hyperacusis and do not recognise its impact on a patient's life. This has become a source of frustration for people experiencing hyperacusis as they seem to be expected to simply get on with life despite their hypersensitivity to noise. Although hyperacusis can have a great impact on the daily life of the sufferers, the topic has attracted little academic interest to date. A search on papers published over the last five years using MEDLINE database revealed that on average only 8 papers per year were published on hyperacusis as opposed to 216 papers per year on tinnitus, 8193 papers per year on HIV and 38468 papers per year on cancer.

The exact prevalence of hyperacusis in the general population is not clear, however, a recent study using an international tinnitus research database revealed that as much as 55% of 1713 patients with tinnitus had hyperacusis too. Patients with hyperacusis were younger, had higher distress and higher rates of pain disorders and vertigo (Schecklmann et al, 2014).

Depending on the severity of hyperacusis some people can cope well with their hypersensitivity and lead their normal life; however, hyperacusis, if not managed properly, can lead to a high level of disability for some leading to emotional disorders and substantial discomfort. Inability to access public services, health and education, recreation and other social interactions are not uncommon among people who experience hyperacusis.

Recent research evidence suggests that specialist cognitive-behavioural and retraining therapies in management of hyperacusis may be beneficial. Although psychological care and support are generally welcomed by many people, it has created rage for others protesting that hyperacusis is not a psychological condition. They report that they suffer from extreme pain when exposed to day-to-day environmental noises and often feel disappointed when clinicians suggest psychological therapies. Clinicians are not clear about what exactly to do for patients experiencing hyperacusis either. In some people hyperacusis may in fact be a symptom of Creutzfeldt-Jakob disease, facial paralysis, head trauma, anxiety, post-traumatic stress disorder, schizophrenia, Williams syndrome, autistic spectrum disorder, Lyme disease, dementia, regional pain syndrome, sensory processing disorders or hearing loss. However, in most people hyperacusis is not related to any hearing or other health condition.

Another controversial subject is the conflict between the clinicians and the patients on psychosocial aspects of hyperacusis. Clinicians mainly encourage therapy programmes enabling the individuals to cope and lead their normal life despite their hypersensitivity to day-to-day noises. They believe that avoiding noise does not address the problem. However, patients who have not benefited from such therapies call for recognition of hyperacusis as a disability warranting reasonable adjustments in public services, education, employment, etc to accommodate their needs.

Public involvement is essential in helping to shape the future of hyperacusis research, health and social care. Anyone affected by hyperacusis or with an interest in this condition could provide valuable information for clinicians and researchers. The conference theme is geared towards just that – Public Involvement in promoting research and guiding clinical practice.

In addition to the expert committees assembled from 20 countries in order to ensure informative days with high educational standard for the delegates, members of public and people who experience hyperacusis are encouraged to attend the conference, join a lay fellow committee, give presentations, and take part in discussions.

In order to improve access to scientific and technical information for participants who do not have any audiology background, a pre-conference introductory workshop is planned for 8th July 2015. The aim of this workshop is to offer appropriate information, support and training allowing lay participants to contribute and benefit fully from the conference.

My team and I look forward to welcoming you to ICH2 in July 2015.

Get the latest updates on Facebook and Twitter. Contact us via: www.hyperacusisresearch.co.uk
Living with hyperacusis...

To find out a patient’s perspective on hyperacusis, Safeeya Habaik interviewed David Boulton, who gives some insights into living with hyperacusis and the support he would value.

What hyperacusis symptoms do you experience, and how do they impact your life? I experience pain at certain levels of volume and pitch. The pain seems to precede actually hearing the noise - I flinch before I hear the sound. Voices can be indistinct, and comprehension is difficult in the presence of competing noises. A number of everyday sounds can trigger misophonia. Socially I feel awkward, as it can be difficult to converse in noisy places. Work can be very tricky. I can be judged as difficult to get on with, when I am assertive in reminding people that their noise is unnecessary. I cannot use a phone, which is enormously frustrating.

What professional treatment have you been offered, and has it been of benefit? TRT, despite the fact that, initially, I had no tinnitus at all. The treatment sparked tinnitus, which settled down once treatment was withdrawn. I am now waiting to begin CBT. As a lifelong sufferer, I believe I may find CBT to be of limited benefit.

Considering your experiences, what would you like to see from clinicians? I would like to be treated in accordance with my symptoms to be assisted in finding practical, “symptomatic relief”. Given techniques to manage my particular tolerances in the day-to-day world.

Are there any coping strategies you already implement in your daily routine? I try to remove irritating noises from my life. Noisy things are taken apart and fixed or oiled to stop squeaks and rattles. This makes it easier to tolerate the noises that cannot be attenuated so easily.

What are your expectations from society in general, in terms of your hyperacusis? As a hidden disability I should like to be listened to, and for others to attempt to understand that the world can seem hostile to me. The adjustments that can be easily made for my benefit will also benefit society at large - a quieter world will be nice for everyone.

What would you say to those that enjoy experiencing noise around them constantly, do you think a compromise can be reached? If people enjoy noise, then by all means they should have it. But, do I have to endure their “passive-noise”? Previously, we had the same arguments about tobacco smoke, and over a period of time attitudes were changed. A compromise is possible; it is our responsibility to assess the actual value of noises (made by beepers, alarms, buzzers) on the lives of the people being served.

In your opinion, what reasonable adjustments can be made by the authorities to improve access to: health/social care, recreation and occupation, for those with hyperacusis? Reduce the amount of noise that is made in public places. Waiting rooms do not need TV’s or radios. Well-planned acoustics in recreational areas could improve the comfort for everyone without eliminating sound. It is also important to have hyperacusis officially recognised as a form of disability.

What do you expect from the upcoming International Conference and how would you like to get involved? I expect there will be influential people who can help to guide the treatment and management of this condition. My own experience is that the treatments are new and are not universally successful. The failures (like my own) are a valuable opportunity to improve the ways that this is treated. I’d like to be involved in challenging some of the current received wisdom. How Hyperacusis is currently described to me by clinicians is not something that I fully recognise as the condition I suffer with. I want my voice to be heard.

If yes, then how would you feel about participating in ICH2 where many international speakers are invited to share their clinical & research experience?

“• Do you see patients with hyperacusis in your adult or paediatric audiology clinics?
• Would you like to know more about audiological assessment & management of this condition?
• Do you work in adult rehab audiology and feel that some of your patients do not get on well with their hearing aids due to their decreased sound tolerance? Would you like to learn how to effectively support these patients?
• Do you see children suffering from hyperacusis? Would you like to know more about evidence based management strategies?

Would you like to talk about your experiences with hyperacusis?
Or have you seen patients with hyperacusis?
Contact us at farhaitkiani@nhs.net
Research update: We keep you up to date on recent hyperacusis research.

### Hyperacusis combined with tinnitus?

Dr. Martin Schecklmann, a member of the ICH2 scientific committee, has recently conducted a large-scale study on people experiencing tinnitus with and without hyperacusis. The results suggested that tinnitus, combined with hyperacusis, should be viewed as a separate subtype of tinnitus. Patients who experience both tinnitus and hyperacusis are more seriously impaired and more vulnerable to auditory and non-auditory sensory stimulation. The foundation has therefore been laid for more detailed research to explore the hypersensitive nature of hyperacusis. We interviewed Dr. Schecklmann to find out more.

**Please tell us about the work you do and the team you work with?**

Our working group in Regensburg (Germany) consists of the laboratory for neural plasticity, the Tinnitus center and the head office of the Tinnitus Research Initiative. We are engaged in clinical and scientific work with all forms of chronic tinnitus, with a special focus on brain stimulation.

**What attracted you to tinnitus and hyperacusis research?**

Both disorders are highly associated with dysfunctions of peripheral (cochlear) and/or neural auditory processing. It has turned out that the switch to reverse these dysfunctions is hidden in the interconnected nature of the peripheral and neural systems, and so it should be possible to cure these conditions in the future.

**Your recent research paper suggests that tinnitus patients with hyperacusis are a specific tinnitus subtype, characterised by increasingly distressing symptoms. What is the clinical importance of these findings?**

These findings should motivate clinicians to explore the tinnitus patients, such as taking a detailed history, to identify hyperacusis and related problems.

### Mechanism of hyperacusis through animal experiments

Interview with Professor Richard Salvi, a member of the ICH2 scientific committee.

**What is your primary area of interest?**

My work in recent years has focused on tinnitus and hyperacusis, but I also continue to work on ototoxicity and noise-induced hearing loss, in particular blast wave exposures.

**What do you think is the source of hyperacusis?**

This is a complex question and clinicians and scientists are only beginning to understand the mysteries of hyperacusis and its causes. The number of scientists working on hyperacusis is very small and the number of papers published on the topic each year is few. Despite these limitations, some general ideas are beginning to emerge.

First, hyperacusis is often associated with hearing loss. Sometimes the hearing loss shows up as a threshold elevation on the audiogram, the “classical” hearing loss. However, some forms of hearing loss are “Hidden” because damage is confined to the inner hair cells or the auditory nerve that connects the inner ear to the brain (see Lobarinas et al., 2013, Hearing Res, 302, 113-20); this type of damage does not show up on the conventional audiogram. Regardless of whether you have a conventional hearing loss (threshold elevation) or hidden hearing loss, the neural activity transmitted from the inner ear to the auditory brain is greatly reduced. Paradoxically, the central auditory system tries to adapt to the reduced neural input by turning up its gain, so called Enhanced Central Gain. Enhanced Central Gain boosts the weak neural signals from the ear, which would normally sound muffled and makes the sounds audible again. However, if Central Gain is too high and overshoots, the neural activity reaching the auditory cortex will be excessive (i.e., Excessive Central Gain). Experimental evidence demonstrating this can be found.
Hyperacusis disappeared when salicylate treatment was discontinued. Now that we know how to assess hyperacusis in rodents, we can use a broad range of electrophysiological recording techniques to identify the region of the brain that are hyper-reactive to loud sounds. If the neural activity in a specific brain region is tightly correlated with behavioural measures of hyperacusis, then the neural activity might represent the “neural signature” of hyperacusis. Our preliminary electrophysiological studies suggest that a number of different central auditory structures and non-auditory structures contribute to hyperacusis (Chen et al., 2013, Hearing Res, 295, 110-113). Like most neurological disorders, hyperacusis may be a multifactorial, multifaceted condition. This is supported by imaging studies in animals that show altered activity in many different regions under conditions known to induce tinnitus and hyperacusis.

What should we try to test on human subjects based on the findings from animal studies?

Human brain imaging studies with structural MRI, functional MRI, MEG, and quantitative EEG offer ways of assessing where brain activity is changing and by how much with sounds of different intensities. A major advantage of human studies is that the imaging results can be combined with verbal and written reports about the severity and nature of the hyperacusis. For example, some individual report that moderate intensity sounds are not only loud, but also evoked feeling of pain.

What area needs to be improved in hyperacusis treatment?

This question is outside my area of research expertise, but from my understanding of the literature sound therapy and counselling seem to provide benefit for many individuals; however some individuals fail to benefit from these modes of treatment. Identifying the characteristics of these “treatment resistant” individuals would represent an important step forward. It would be important to be able to differentiate patients with different types of hyperacusis for example those that only have loudness tolerance problems vs. those with loudness tolerance and pain or anxiety.
1 - Hyperacusis is an oversensitivity to sound that has perceptual, psychological and social dimensions. Depending on the patient, hyperacusis can be related to the loudness of the sound and/or to the emotional response (annoyance or fear) to sound.

2 - There is a growing awareness that children as well as adults experience symptoms of hyperacusis or misophonia, which are real and are experienced by almost 9% of the population.

3 - If you believe you are becoming hypersensitive and extremely annoyed by loud sounds, ask your general practitioner (GP) for a referral to an ear specialist (otolaryngologist) or audiologist with experience dealing with hyperacusis, sound annoyance or misophonia.

4 - The exact mechanisms that give rise to hyperacusis are not clear, but there is growing awareness that functional changes within the central nervous system are involved.

5 - Evidence gathered over the past two decades suggest that hyperacusis may be related to increased gain (enhanced output) in the central auditory pathway and to increased anxiety or emotional response to loud sounds.

6 - Not everyone with hyperacusis needs treatment from a professional. However, there are many people who have benefited from seeing a hyperacusis specialist most of whom work in Audiology departments that specialize in hyperacusis.

7 - Various counseling and therapy approaches seem to be successful in management of hyperacusis.


Key outcomes from the First International conference on Hyperacusis: Causes, Evaluation, Diagnosis and Treatment in 2013.
Hi Dr Storch – thank you very much for taking part in this interview for the ICH2. First, please tell us a little about yourself.

I completed my PhD in clinical psychology at Columbia University. I value the integration of science and research to provide clinical care for individuals. For fun, I spend time with my family, travel, and play soccer.

Please tell us a little about the University of South Florida and your clinic.

The Rothman Center offers an integrated practice of clinical care for individuals with OCD, autistic spectrum disorders and other related disorders. This is all-encompassing and multi-disciplinary, from diagnosis and evidence-based treatment to education and research. The Center’s and allied health care professionals function as an interdisciplinary team to deliver various safe and effective treatments which focus on the whole person and the family unit. This goal is consistent with the increasing interdisciplinary nature of health-related research. Only by holding therapies to the highest standards of evidence will we best accomplish this broad aim. You have published over 300 peer reviewed articles - what inspires or motivates you in your research? Simply put – it is helping people achieve wellness and live the life that they desire.

What aspect of research do you most enjoy? I enjoy formulating the question, helping people in the context of our therapy trials, writing up and disseminating the results.

You have had considerable experience with children with OCD and anxiety. Which treatment methods do you feel work best?

Exposure and response prevention (ERP), which is a cognitive-behaviour based therapy, is the single most effective treatment for OCD. This involves facing the situation or thought which causes the anxiety and then refraining from the compulsive behaviour. It takes a high level of commitment, but over time the level of anxiety decreases. Antidepressants are also an effective treatment for OCD. A combination of ERP and anti-depressants may be appropriate for severe cases.

You have also had experience with children with hyperacusis. What interests you most about hyperacusis?

Beyond the nature of it, the condition is quite impairing to the affected person and their family. I am most excited about studying interventions to help those affected.

What are your views on the similarities between hyperacusis in children and childhood OCD/anxiety?

Learning from Obsessive Compulsive Disorder

Currently, there is very little research regarding the management of hyperacusis in children. Children may report similar symptoms to adults, where everyday sounds are intrusive or painful, and they may also have hearing within normal limits. OCD is a condition which may co-occur with hyperacusis...

To find out more about the management of OCD and how this could be applied to hyperacusis, Natasha Phillips interviewed a member of our conference scientific committee, Dr Eric Storch (University of South Florida), who specialises in the cognitive behavioural management of adults and children with OCD and its related disorders.
Professor Peter Beresford OBE, from Brunel University will give you insights about his forthcoming lecture at ICH2 on “Enabling Everyone’s Effective Involvement” which is planned for 10th July 2015. His presentation will seek to offer practical help and improve understanding for all seeking to support the more effective involvement of people affected by hyperacusis. It will explore this in relation to involvement in policy, practice, research and evaluation, drawing on evidence. It will pay particular attention to issues of access and inclusion, drawing on a national Department of Health research and development project exploring the barriers restricting people’s involvement and how these can be overcome. The presentation will also take account of the practical realities of the current practice and policy environment. Peter is the director of the Centre for Citizen Participation at Brunel University. He is a long term user of mental health services and Chair of Shaping Our Lives, the user controlled and disabled people’s organization and network. He has a longstanding involvement in issues of participation as an activist, educator, researcher and writer. He is joint editor with Sarah Carr of Service Users, Social Care And User Involvement, 2012, Jessica Kingsley.

Professor Brian Moore, from the University of Cambridge will give you some key insights about his forthcoming lecture at ICH2 on possible mechanisms underlying loudness hyperacusis which is planned for 9th July 2015. In addition, we will learn much more about Brian’s fascinating career as a research leader in the field of hearing science plus his personal interests. Brian has written or edited 17 books and over 590 scientific papers and book chapters.

Professor Deepak Prasher, Editor in Chief of the Noise and Health journal, will give you some fascinating insights about his forthcoming lecture at ICH2 on the latest research findings on noise sensitivity and effect of noise pollution in Metropolitan cities on people’s health and well being which is planned for 10th July 2015. During his exceptional career as a clinical scientist, researcher and consultant Deepak has made substantial contributions to understanding the effects of environmental noise on hearing. His work has been supported by three major European Commission grants. He has written or edited 6 books and over 100 scientific papers.
Call for abstracts:

It is our great pleasure to invite you to take part in International Conference on Hyperacusis by submitting an abstract for an oral presentation, poster presentation, symposium, workshop or panel discussion. Deadline for abstract submission is 28th February 2015. Examples of suggested topics are:

- Public involvement in hyperacusis research
- Public involvement in guiding clinical practice
- Hyperacusis and disability
- Improving access to health, education, and social services for people with hyperacusis
- Patients’ perspectives on hyperacusis definition, assessment and treatment
- Causes, mechanism, diagnosis and treatment of hyperacusis
- Noise sensitivity, Misophonia, Annoyance hyperacusis, 4S (Selective/Soft Sound Sensitivity Syndrome)
- Noise anxiety
- Noise and health
- The relationship between hyperacusis and tinnitus
- Experimental studies and models
- Loudness Discomfort Levels
- Evaluating impact of hyperacusis using self-report questionnaire

Get the latest updates on Facebook and Twitter:

Hashir Aziz @HashirAziz
https://www.facebook.com/hyperacusisconference

<table>
<thead>
<tr>
<th>Registration category</th>
<th>Deadline</th>
<th>Fee (healthcare professionals)</th>
<th>Fee (non-healthcare professionals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early bird</td>
<td>15th May 2015</td>
<td>£350</td>
<td>£125</td>
</tr>
<tr>
<td>Regular</td>
<td>After 15th May</td>
<td>£395</td>
<td>£150</td>
</tr>
<tr>
<td>Late</td>
<td>On the day</td>
<td>£500</td>
<td>£200</td>
</tr>
</tbody>
</table>

*Student rate is only available until 30th March 2015. Proof of student status is required.

Registration for ICH2: To register visit: www.hyperacusisresearch.co.uk

Get up to date with all the news about

- Key note speakers and lectures planned for the 2nd international conference on Hyperacusis
- Hyperacusis research
- Specialist training
- Hyperacusis assessment and management
- Interviews with experts and patients
- Social support for people with Hyperacusis
- And in the final issue the Outcome of the conference

Subscribe for FREE just by emailing us at admin@hyperacusisresearch.co.uk to get your online copy of the ICH2 news every 2 months from now until August 2015.
Also Meet...
London attractions close to the conference venue

British Museum (2 minutes walk)
The National Gallery (25 minutes walk)
Westminster (13 minutes drive)

Harrods (18 minutes by tube)
St Paul's Cathedral (28 minutes walk)
Regents park (23 minutes walk)

Buckingham Palace (35 minutes walk)
Piccadilly (25 minutes walk)
Oxford street (23 minutes walk)

London Bridge (14 minutes drive)
Greenwich (30 minutes drive)
Madame Tussauds (6 minutes drive)

*Student rate is only available until 30th March 2015. Proof of student status is required
Tinnitus & Hyperacusis Therapy Masterclass

16-20 March 2015
Venue: Birkbeck College, University of London

Course Tutor:
Dr. Hashir Aazh
University of London, UK

Invited Speakers
Professor Brian C. J. Moore
University of Cambridge, UK
Dr. Don McFerran
Consultant ENT Surgeon at Colchester Hospital, UK
Professor Richard Salvi
State University of New York at Buffalo, USA

Course Website
http://tinnitustherapy.org.uk/

“This specialist course has been accredited with 3.0 CEUs by AAA, 30 CPD by BAA and BSHAA, and 40 CPD by Audiology Australia.”