

BACD NEWS

SPRING
2020

The official newsletter of the British Academy of Childhood Disability



HOW OTHERS SEE YOU IS NOT IMPORTANT,
HOW YOU SEE YOURSELF MEANS EVERYTHING

(c) Imelda Bell of Photography by Imelda

Welcome to our new look!

Dr Yasmin DeAlwis, Editor

Welcome to our new online edition of the newsletter. I hope you will agree with me that this change has been inevitable given concerns with climate change. In addition to saving the planet, we now have the ability to expand the newsletter so that important articles are published in a timely manner.

We are very pleased to run a chapter on 'Childhood hearing impairment' in keeping with the theme of this year's ASM. These articles are very comprehensive and written by members of BAPA. They will undoubtedly update your knowledge in the subject. I always find myself looking up which investigations to do at what age and aim to keep these articles as a reference for my practice.

The BACD inaugural Gala dinner was held prior to the Annual Scientific Meeting (ASM) at the Crown Plaza Sheffield, where many achievements were celebrated. Congratulations to Jill Cadwgan and Belinda Crowe for organising such an inspiring and fun night. We have captured some of the highlights from the night on page 3.

We hope you found the ASM useful opportunity to learn as well network with colleagues. I'd like to thank Catherine Tuffrey for putting together such a great programme with fantastic speakers. A review of the ASM will appear in the summer edition of the newsletter.

THIS IS AN OPEN ACCESS, SHORTER VERSION OF THE SPRING 2020 BACD NEWS.

TO READ THE FULL VERSION:

- BACD Members should log into their account on the bacd website
- Join BACD at www.bacdis.org.uk/pages/2-membership

BACD

British Academy of Childhood Disability

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www.bacdis.org.uk

*BACD is registered in England and
Wales under charity number 1177868*

**PROMOTING THE HIGHEST
POSSIBLE STANDARD OF CLINICAL
CARE FOR DISABLED CHILDREN AND
YOUNG PEOPLE, AND THEIR
FAMILIES**

Member Benefits

- Discounts on BACD Conferences
- Quarterly newsletter and monthly e-news
- Discounts on Paediatric Disability Distance Learning Courses
- Reduced subscription to Developmental Medicine & Child Neurology journal
- 20% discount on all Mac Keith publications

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BACD Gala Dinner and Achievement Awards



Award Winners

Lifetime Achievement Dr Val Harpin and Prof Gillian Baird

Inspirational Young Person Naveed Hafeez

Star Quality Ethan Peacock

Inspirational Professional Susie Turner

Inspirational Parent Carer Carlie Gul

Inspirational Sibling Liam and Oliver

Best Photo that captures ethos of BACD (see front page)

Imelda Bell's photo of Caitlin Goodsell

We were delighted that so many friends attended the Gala Dinner and the first ever Achievement awards to formally celebrate BACD becoming a charity, as well as inspirational achievements from colleagues, and children, young people and their families affected by disability.

The summer edition of the newsletter will showcase the winners of the inaugural Achievement Awards.



Lifetime Achievement Award - Dr Val Harpin
Many thanks to the BACD for giving me one of the first of these exciting honours. When I learnt of the award I was prompted to think about my career. I realise that I was fortunate in many ways. I was able to include research and teaching in my full time NHS clinical role; both of which taught me a great deal and hugely enriched my experience and I believe that of my patients and their families.

When Professor Sir David Hall suggested we needed to support training for doctors working with disabled children and young people I was the lucky colleague given the challenge. When Neurodisability was becoming recognised as a paediatric speciality, I was fortunate to be elected the first chair of the BACD.

I have been very lucky to be in the right places at the right times with the right colleagues, here in Sheffield and previously in Nottingham and Oxford.

I am grateful to all the amazing medical secretaries, therapists, nurses, psychologists, education professionals, social workers, administrators, managers, doctors and other colleagues who supported me through good times and sometimes really bad times. MDTs really do work.

A massive thank you too to all the children, young people and families with whom I have had the privilege to work for over more than 30 years. You taught me so much. It has been such a pleasure and support to share my passion and enthusiasm with my friends in the BACD.

Congratulations on becoming a Charity. Thank you from the bottom of my heart.

Val



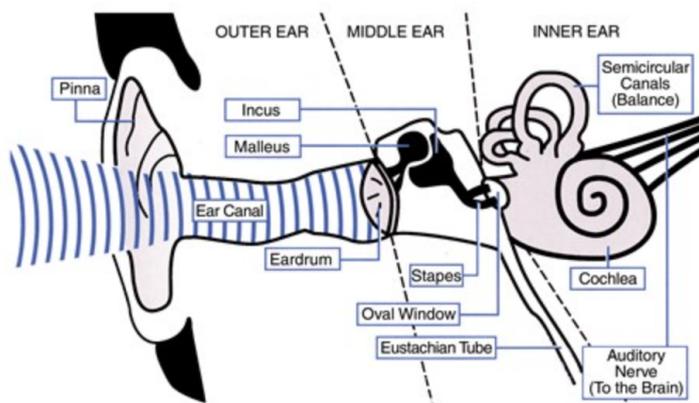
Why do we need so many hearing tests?

Dr Rosa Crunkhorn, Specialty trainee in Audiovestibular Medicine and Dr Shankar Rangan, Consultant Audiovestibular Physician, Wirral University Teaching Hospital

INTRODUCTION

There is an ever-expanding range of diagnostic and screening tests available both for paediatric hearing and vestibular assessment. This article aims to demystify the different hearing tests available for children, as well as clarify the rationale for different approaches.

How hearing works – a brief reminder



National Deaf Children's Society

The **outer ear** funnels sound waves down the ear canal towards the tympanic membrane, causing vibration of the ear drum which is conducted through the **middle ear** by the three ossicles and into the **inner ear** via the oval window, causing the endolymph and hair cells within the cochlea to move. This movement is transduced into electrical energy which travels via the cochlear nerve to the brain, where it is perceived as sound.

TYPES OF HEARING LOSS

Problems in different parts of the hearing pathways cause the different type of hearing losses:

- Conductive – blockage to the passage of sound through the outer and middle ear, commonly “glue ear”. Usually temporary but can be permanent e.g. ossicular abnormalities.
- Sensorineural – inner ear usually within the cochlea, which is a permanent hearing loss.
- Mixed – a combination of conductive and sensorineural hearing loss
- Central – problems with central processing of sound with normal peripheral hearing assessment
- Auditory neuropathy spectrum disorder – a heterogeneous group characterised by dysfunction of the inner hair cells of the cochlea, the synapses and/or the auditory nerve itself. This leads to difficulties with auditory perception.

LEVELS OF HEARING LOSS

The British Society of Audiology describe the different levels of hearing loss as below:

Degree of hearing loss

Normal hearing	≤ 20 dB HL
Mild	21 – 40 dB HL
Moderate	41 – 70 dB HL
Severe	71 – 95 dB HL
Profound	> 95 dB HL

Even a mild hearing loss has a significant impact on a child's ability to hear and discriminate speech, particularly in noisy situations such as a classroom. A useful hearing loss simulator:

www.youtube.com/watch?v=TD5E88fFnxE

HOW CAN WE CLASSIFY THE DIFFERENT TYPES OF HEARING TESTS?

Hearing tests can be classified as objective or subjective based on whether the results depend on a response from the child or not. A Screening test give a pass / fail for a specific parameter and Diagnostic test informs of specific hearing levels, degree and type of hearing loss. A Freefield or Soundfield test inform about child's hearing when both ears are working together, more closely reflecting day-to-day life. Speech testing inform about functional difficulties in hearing within a classroom setting. There are specific tests for auditory processing disorder.

Objective tests of hearing

- Otoacoustic emissions (OAEs)
 - OAE's describe sounds produced by the outer hair cells of the cochlea in response to a stimulus sound which are transmitted back to the outer ear. Recording is affected by middle ear problems and noise.
 - Transient Evoked Otoacoustic Emissions (TEOAE's) present at multiple frequencies suggest that hearing is better than 30dBHL
- Auditory Evoked Potentials (Automated Auditory Brainstem Response- ABR, Auditory Brainstem Response, Auditory Steady State Responses, Middle latency responses, Cortical Evoked Responses)
 - ABR, the most commonly used evoked potential test assesses the auditory nerve and brainstem response to acoustic stimuli.

- o ABR can be checked at different frequencies to give a representation of the child's overall hearing. ABR is also used in the diagnosis of auditory neuropathy.
- Acoustic immittance studies (Tympanometry and Acoustic reflexes)
 - o Tympanometry provides information about middle ear status, e.g. glue ear or eustachian tube dysfunction
 - o Acoustic reflexes assess the reflex pathway (afferent pathway cranial nerve VIII; efferent pathway cranial nerve VII) in response to loud sound. Stimulating the ear leads to a reflex contraction of the stapedial muscle which can be recorded at screening or diagnostic levels giving information both ipsi- and contralaterally

Objective testing plays a vital role in the newborn hearing screen programme (NHSP) in the UK, specifically with the use of OAE's and ABR6. If there is no clear response on two tests of OAE's, babies are assessed with automated ABR testing. If no clear response is recorded on automated ABR, babies are referred for diagnostic ABR which must be performed within 4 weeks of birth as early intervention in hearing loss leads to better outcomes for the child.

Targeted follow up of hearing is also arranged for certain high-risk groups for example babies with Down's syndrome, certain congenital infections, Craniofacial abnormality, confirmed syndrome associated with hearing loss, etc.

Subjective tests of hearing

Behavioural tests of hearing assess the child's whole auditory pathway and require a child's response to hearing a sound. The different tests are illustrated briefly below, with links to video's which demonstrate much more clearly how the tests are performed.

- Behavioural observation audiometry (BOA): This test uses observation of an infant, usually aged 3-6 months, during exposure to sounds. Infants may show a startle response at suprathreshold sounds or may show more subtle responses such as changes in sucking or blinking for sounds closer to the hearing threshold.
- Visual reinforcement audiometry (VRA): This test is commonly used in children from age 6 months to 2 ½ years. The test conditions the child to turn when they hear a sound, by presenting a visual reward, for example a video screen with cartoon pictures. Different frequencies are tested either in soundfield (ears working together) or with inserts (ear specific testing). Bone conduction levels can also be measured.
www.youtube.com/watch?v=S45H3i2ulto

- Distraction testing: This tests the ability of a child from 6-8 months to turn and localise to a sound. The child's attention is held in front by a distractor. A second tester presents different sounds from behind. A positive response is a clear turn towards the sound on 2 out of 3 presentations. This test is not ear specific but can be very useful to give an idea of functional hearing levels.

www.youtube.com/watch?v=LK5ExH4KwBI

- Performance audiometry / Play / Pure Tone Audiometry: children aged 2 ½ - 3 years are conditioned to complete a task when they hear a sound, e.g. put a man into a boat. Threshold levels are measured by seeing the quietest response sound the child can respond to. Slightly older children can progress to play audiometry, wearing headphones with the same game. **Pure tone audiometry (PTA) is the gold standard hearing test in older children.** PTA follows the same principle as play audiometry – wearing headphones and responding each time the sound is heard. As a child gets older masking can be performed if needed.

www.youtube.com/watch?v=rr2m4fmirAM

- Speech tests: Assessments looking at speech discrimination, speech understanding, and word recognition can be used to give further functional hearing information, and to support the findings of behavioural testing. There are a number of age appropriate tests available, for example the McCormick Toy Test can be used in children from the age of approximately 2 ½ years.

Testing the more complex child

Which test to use depends on whether the child is developmentally ready to turn their head to localise a sound, whether vision limits the use of visual rewards, a child's attention and concentration and other health conditions and factors on the day rather than age alone.

A routine hearing check to assess whether the child can hear speech sounds adequately for their speech and language development a freefield assessment of hearing can be sufficient. Explaining to parents that this test may not detect unilateral hearing loss is essential.

Hearing test may be modified for children with neurodevelopmental difficulties such as autism, ADHD or learning difficulties. Children may not respond as they are just not interested, particularly at quieter levels. Use whatever methods will gain as much information as possible.

Congenital Cytomegalovirus and Hearing loss

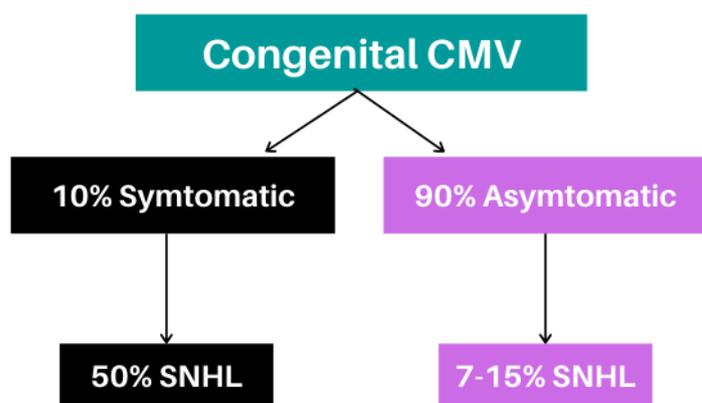
Dr Martina Stones, Associate Specialist,
Community Paediatrics, Tayside

WHAT DO WE KNOW?

Congenital CMV infection is the most common, non genetic cause of permanent hearing loss.

WHAT IS CYTOMEGALOVIRUS (CMV)?

- Virus - part of the Herpes family
- Very common - many adults are seropositive (CMV causes a mild, febrile illness)
- Spread via close contact- urine, blood, breast milk, faeces
- Infected babies can shed virus for many years
- If primary infection occurs during pregnancy transmission rate to foetus is 30-40%
- 10% of infected foetuses will be symptomatic (ventriculomegaly, periventricular calcification, cataracts, petechiae/ purpura, hepatosplenomegaly, IUGR)
- 90% are "asymptomatic" at birth - but up to 15% of this group will develop hearing loss



Hearing loss in Congenital CMV (cCMV)

- Late onset hearing loss is common- more than 50% of children diagnosed with cCMV associated hearing loss have normal hearing at birth and pass their newborn screening.
- Deterioration in hearing in cCMV is a common finding- unilateral loss can become a bilateral loss, or mild losses can become severe.
- Deterioration in hearing has been reported up to late childhood but most common in under 8 year olds.
- Type of hearing loss can be variable.
- Balance difficulties are also common.

DIAGNOSIS

- Congenital CMV is diagnosed at birth in symptomatic children- urine/saliva viral culture or PCR.
- In children identified with hearing loss from the newborn hearing screen
 - if day 21 or before then urine/saliva viral detection
 - if over 21 days of age then CMV IgG and, if positive, CMV PCR on neonatal stored heel prick sample to confirm presence of virus at birth and not a post natal infection.

Note local variation in length of time blood spots are stored for- may affect ease of diagnosis.

MANAGEMENT

In discussion with local virology/ infectious disease paediatricians:

- Anti viral treatment for symptomatic cCMV -
- Recommended 6 months of oral treatment - 16mg/kg/dose valganciclovir oral solution twice daily
- If hearing loss diagnosed and cCMV confirmed prior to 1 month consider treatment
- Antiviral treatments have been shown to reduce the risk of hearing deterioration. Known side effects are short-term neutropenia.

What can be done to reduce incidence of cCMV hearing loss?

Infected babies continue to shed virus for many months. Therefore education of pregnant mums with toddlers, pregnant women working in nursery/ child care settings, workers of child bearing age in high risk workplaces is vital. These groups should be advised to:

- Try to not share food, cups or cutlery, or put child's dummy in your mouth. Give kisses on the head rather than mouth.
- Clean hands after touching a child's urine or saliva.
- Wash hands well for 15-20 seconds with soap and water.
- Wash items that may have been in contact with a child's saliva or urine.

For further information visit www.cmvaction.org.uk



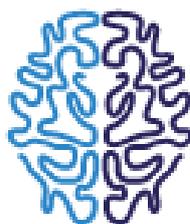
The British Association of Paediatricians in Audiology (BAPA) was inaugurated in 2007 as an association of paediatricians practising audio-vestibular medicine. BAPA has its roots in the former British Association of Community Doctors in Audiology (BACDA) an organisation begun in 1985 by a small group of clinicians dedicated to the development of high quality hearing assessments for children.

www.bapa.uk.com

Research Update

Professor Jeremy Parr, Chair, BACD Strategic Research Group

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Castang
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PAUL POLANI AWARD 2020

This year's award was held in conjunction with the Chartered Society of Physiotherapists Charitable Trust, which co-funded the £60,000 award with the Royal College of Paediatrics and Child Health.

The Award called for a study of clinically relevant physiotherapy interventions for children with neurodevelopmental conditions, disability, and their families.

The 2020 Award has been awarded to **Dr Sarah Crombie**, Expert Clinical Academic Physiotherapist and Research Fellow, Chailey Clinical Services, Sussex Community NHS Foundation Trust (SCFT) and MDT colleagues for the study:

Breathe-Easy: a pilot study to examine the acceptability and feasibility of a novel night-time postural management night-time intervention (PMN-TI) to improve respiratory health of children with complex neuro-disability

We hope to bring you a summary of the project in the June newsletter.

THERAPY PRIORITY SETTING WORKSHOPS

Members will recall that BACD funded the priority setting partnership to identify the top 10 unanswered questions in childhood disability research. The number one question identified was therapy interventions. To date, no studies have been funded relating to this priority.

With funding from the Castang Foundation, the BACD Strategic Research Group (SRG) delivered a therapy-specific priority setting process, including two workshops in London and Leeds with therapist delegates and NIHR HTA in September 2019.

Five clear priorities relating to speech and language therapy, physiotherapy, and occupational therapy were identified, as well as a longer list of other important topics. This has been reviewed by NIHR and worked up as research questions/PICOS by the SRG, which have now entered the NIHR HTA development pipeline. It is hoped that they will become the subject of multiple commissioned calls. Lindsay Pennington has written report with other SRG therapists (especially Sarah Crombie, Chailey and Rob Brooks, Leeds).

BACD-CASTANG FELLOWSHIP WORKSHOPS

Cohort 1 Fellows have been awarded £1.5 million in grant funding since the Fellowship programme commenced. The Castang Foundation is positive about the impact and is interested in potentially supporting further awards/related initiatives.

Cohort 2, year 2 was delivered by Jennifer McAnuff, Jeremy Parr, and others from SRG, along with invited clinical academics for two days of workshops prior to the BACD annual scientific meeting in March 2020. The Cohort 2 Fellows are progressing well and feedback has been positive.

There is a dedicated RESEARCH section on the BACD website, where you can find information on:

- Strategic Research Group
- Castang Fellowship programme
- Awards
- Priority Setting Partnerships

www.bacdis.org.uk/pages/16-research

Paediatric Disability Distance Learning Courses

Online learning resources to support professionals working with disabled children and their families

PAEDIATRIC NEURODISABILITY DIPLOMA

This course is recommended for all Paediatric Neurodisability grid trainees in the UK to complement the grid training programme and provides a useful framework to gain the expected competencies. It would also be excellent training for any medical specialist in Paediatric Neurodisability in the UK and overseas.

EPILEPSY: DIAGNOSIS, DESCRIPTION, MANAGEMENT AND DISABILITY

This course is for any member of the multidisciplinary healthcare team who wants to improve their knowledge and understanding of epilepsies, their assessment, description, management and associated conditions, and to improve their awareness of resources to better inform and support children, young people and their families.

ADHD AND COMORBID CONDITIONS

This course is intended to support learning for specialist nurses, paediatricians and other health professionals working with children and young people with ADHD and their families.

AN INTRODUCTION TO PAEDIATRIC DISABILITY AND CLINICAL ASSESSMENT

This course is intended to support learning for specialist nurses, paediatricians and professionals working with disabled children and young people and those following different developmental pathways.

AUTISM, SPEECH, LANGUAGE AND COMMUNICATION NEEDS IN CHILDHOOD

This course is for professionals involved with assessment and support for children and young people with speech, language and communication needs, including autism spectrum. This includes community, general or specialist paediatricians and allied health professionals, particularly speech and language therapists, school nurses, teachers, SENCO's, educational psychologists and classroom support assistants.

COMING SOON

Please keep checking our
website for new courses

For further information and application details visit:

www.sheffieldchildrens.nhs.uk/about-us/careers-and-opportunities/courses/paediatric-disability-distance-learning/