

*Presentations at BACDA Study Day  
"Clinical and Professional Development"*

*An Introduction to Auditory Steady State Response (ASSR) or Steady State Evoked Potential (SSEP) testing  
Dr Peter Watkin*

Auditory Steady State Responses (ASSR) can be electrophysiologically recorded from the brain in response to a continuous, periodically changing stimulus. A tone can therefore be used to elicit the response and employing a modulation frequency of >60Hz allows frequency specific objective testing of sleeping neonates. The presence of a response can be measured using phase coherence and other statistical strategies, and this increased objectivity offers another potential advantage. The urgent need to obtain threshold information across the frequency range in infants requiring habilitation and hearing aid fitting has re-awakened interest in this technique. The stimuli employed, the response measurement and recording techniques are presented. However the relationship between the ASSR thresholds and the actual hearing levels in early infancy require cautious interpretation. The data available and the plans for expanding the research through the NHSP are presented.

#### **Introduction**

Universal Neonatal Hearing Screening Programmes are being rolled out throughout the UK. The diagnostic assessment of screen positives to specify both type and degree of hearing impairment is essential and requires the employment of test batteries usable on infants. Air conduction click ABR has been employed as the major component of such batteries, and in many series the results have confirmed good correlation with behavioural hearing at 2-4 kHz. Follow up of 184 neonatal ABRs undertaken by the audiology service at Whipps Cross on neonates with non progressive PCHI confirmed a correlation coefficient of 0.9 between the click ABR threshold and the subsequent PTA average between 2 and 4 kHz. This correlation held high for other frequencies when the hearing loss was flat, but when there was normal hearing at 1kHz and below the correlation fell to <0.5. Auditory measurement over the speech frequencies clearly requires additional techniques. The NHSP recommends the use of brief tone ABR testing. However this presents some challenges and the alternative of ASSR may offer advantage. ASSR machines are now commercially available the systems having been developed by research undertaken since the 1980s in Canada (Picton, John, Stapells, Lins, Perez-Abalo), and in Melbourne (Rickards, Rance, Cohen, Cone-Wesson).

Definitions - Transient evoked potentials are elicited when there is a rapid change in auditory stimulus and the response is recorded before the next stimulus is presented. Steady state potentials are elicited by stimuli presented at a high rate so that overlapping of the responses occur. The periodically changing stimulus results in a periodic response.

#### **Stimuli**

Although a large variety of periodic stimuli have been used those employed for clinical testing are usually tones of known frequency (known as the carrier frequency - CF). The CF is amplitude modulated. Increasing the depth of modulation increases the response as does introducing a

slight frequency modulation. Thus the Melbourne system uses tones with 100% depth of AM and 20% for FM. It is the envelope of the tone (i.e. the modulation frequency and not the carrier frequency) which evokes the response. Modulation frequencies from 4-400Hz can be used but the response is best elicited with 40Hz modulation in awake adults. This 40Hz response is affected by sleep and in infants and children frequency modulation rates >60Hz are more effective. Effectiveness is also dependent upon carrier frequency and rates such as 72 Hz, 85Hz and 97Hz are used for 500Hz, 1500Hz and 4000Hz for testing sleeping babies in the Melbourne system. Bone conduction and sound field stimuli can be used but within the context of neonatal threshold testing the tone is delivered through earphones. Physiological ASSR thresholds are measured by reducing intensity and conversely the availability of intensities up to 120dBHL allows testing at higher levels than ABR.

#### **Measuring the Response**

Any waveform can be measured in either the time or frequency domain. ABR characteristically employs the former by measuring waveforms and peak and trough latencies. SSEPs can also be measured in this way, but because the response remains repetitively constant over long periods, measuring in the time domain is less useful. The alternative is frequency analysis, and this is more useful for a continuous periodic response. Fourier analysis measures the response at discrete frequencies and from this the amplitude and phase of the response at that frequency can be calculated. The results can be displayed in two ways. The amplitude/ frequency spectrum plot is familiar to most in the analysis of TEOAE waveforms. However the second way of displaying the result is by showing response phase as a vector on a polar plot. The position of the vector on the polar plot allows an assessment of whether responses are time locked to the envelope of the stimulating waveform. The distribution of a sample of phase vectors can be statistically assessed by of a response is a major advantage of ASSR. The phase delay of the response from the stimulating envelope also reflects the latency of the SSEP – but because it is not possible to be sure that the phase delay has not included additional whole waves, it is referred to as apparent latency. This concept of latency is however still useful. The latencies of 20-41 ms for the 40Hz response as opposed to 9-13 ms for the >90Hz response points to different cerebral sources. The former response reflects cortical activity and the latter modulation rate (as used in children) reflects brainstem activity.

#### **Recording**

Generally this is single channel using high forehead and mastoid or neck electrode placement. The Melbourne equipment records responses to single frequencies presented monaurally. The Ontario equipment allows the additional possibility of using different carrier frequencies with different modulation frequencies applied in different ears

for simultaneous recording. Although there are some interactions which reduce the response amplitudes from multiple simultaneous recording it is considered that for high modulation rates up to eight simultaneous stimuli (four per ear) can be used. The interactions at higher stimulus intensities make this multiple recording less useful when hearing impairment is present, but at moderate or low intensities it increases recording efficiency.

## **Audiometry**

The main purpose of this test is to provide an objective frequency specific measure of hearing and therefore it is necessary to predict behavioural threshold from the recorded physiological threshold. The relationship has been analysed for children and adults with normal hearing and hearing loss. The use of the regression coefficient and the intercept of the regression line on the y axis of the scatter plot predicts the relationship between thresholds – but the statistical relationship is dependent upon the recording methods. The single frequency, monaural stimulation equipment gave a regression coefficient of 1.18 at 1kHz with an intercept at –26dBHL. A 60dBHL physiologic threshold would therefore equate to a 45dBHL behavioural threshold. Using the multiple simultaneous stimulation technique for the same frequency regression analysis gave a coefficient of 0.91 and an intercept of –4dBHL. A 60 dBHL ASSR response using this equipment would therefore have equated to a 51 dBHL behavioural threshold. The latter equipment therefore produces physiological thresholds closer to behavioural levels. However this was achieved by prolonged testing around threshold (15 mins as opposed to 1.5 mins using the single tone testing equipment). In fact more important than the absolute regression values, is the degree of confidence that such predictions can be made and this is determined by the spread of physiological thresholds that are achieved for a given hearing loss. Importantly the spread improves with increasing degree of hearing loss and also increasing carrier frequency. The prediction is therefore most accurate for high frequency sensori-neural deafness.

## **Normative Values in Neonates**

The corollary from these findings could therefore be that these responses are too variable at the lower frequencies to accurately predict normal hearing or a mild or moderate loss. The largest survey of 337 well babies aged 1-7 days confirmed physiological thresholds of 41 dB ( $\pm 10$ ) at 500Hz; 24dB ( $\pm 9$ ) at 1500Hz and 35dB ( $\pm 11$ ) at 4000Hz. No other test within the neonatal battery was used and temporary conductive losses were not excluded. These measures were repeated at Whipps Cross where temporary conductive losses were excluded and the results confirmed a physiologic threshold of 36dB ( $\pm 11$ ) at 500Hz; 31dB ( $\pm 11$ ) at 1000Hz and 32 dB ( $\pm 9$ ) at 4000Hz. The thresholds were compared with a group of babies with a temporary conductive loss and their thresholds of 55dB ( $\pm 15$ ); 51dB ( $\pm 10$ ) and 56dB ( $\pm 19$ ) at the 3 frequencies. The group of babies with a conductive loss therefore had significantly raised ASSR thresholds. The technique was sufficiently sensitive to identify differences in the average thresholds of babies with a mild or moderate conductive loss. However predictably there was a wide spread of physiologic threshold and the overlap in the distributions, meant that (in common with most other audiometric measures), steady state physiological thresholds by themselves could not differentiate individuals with normal hearing from those with a temporary conduction defect.

## **Future Developments.**

Steady State response recording is most likely to be useful for measuring the degree of hearing impairment across the frequency range for those with a moderate or worse degree of sensorineural deafness. Whilst those instrumental in the fundamental research into the clinical machines that are now commercially available, argue that the technique is ready for clinical use. However they urge cautious interpretation. They also note that we need much more normative data and data on infants with hearing loss. This is currently being planned through the NHSP with distribution of machines for a multi-centre evaluation of ASSR in true cases identified through the neonatal screen. Additional research is also being undertaken into the role of these responses in demonstrating gain from hearing aids, and this may also benefit the management of neonates identified by the NHSP.



## ***Newborn Hearing Screening Wales - Care Pathway*** ***Dr Amanda Roberts***

An universal newborn hearing screening programme is being implemented in Wales in 2003 and 2004. The hearing screening for babies is offered to mothers who reside in Wales and aims to identify babies with bilateral significant hearing impairment of 40dBHL. The screening programme has a responsibility to ensure that adequate habilitation services for 0-2 years are available.

A Working Group of the Newborn Hearing Screening Wales Project Board was established to develop a Care Pathway for assessment and habilitation of babies identified by screening.

### **Care Pathways**

- 1 allow a multidisciplinary team to co-ordinate care for individual babies, taking into account clinical and professional judgement
- 2 offer the opportunity for 'family friendly' service provision
- 3 offer opportunities for collaboration between professionals and increased awareness of roles.
- 4 can be used to support clinical effectiveness, audit and risk management

Newborn Hearing Screening Wales is supporting the introduction of the Care Pathway for assessment and habilitation by Early Years Support Teams throughout Trusts in Wales.

## *What benefits, whose perspective?*

### *A summary of the treatment issues in OME resolved by the TARGET RCT*

*Professor Mark Haggard*

Ventilation tubes (VTs - “grommets”) are nowadays placed more sparingly than formerly. Although partly due to the more sober latter-day look at the restricted evidence on effectiveness from RCTs on young children, it is largely due to economic and managerial forces within the NHS organisation and funding. Changes in the related health beliefs have probably been less influential. ENT surgeons still differ greatly in their intervention rates and criteria. The patient choice agenda, whilst not fundamentally hostile to effectiveness, is displacing the recent hard-won emphasis on cost-effectiveness in the NHS, and is in practice reducing the ability to perform the high-quality research that is able to make choice meaningful, ie by informing it. Our research results emerge into an ever-changing context.

On traditional issues (e.g. efficacy results on HLs from VTs, fewer re-insertions after adjuvant adenoidectomy) TARGET, the UK multi-outcome trial on cost-effectiveness, is in line with older trials. However, with TARGET on the over 3.5 year age group and two recent trials in younger children from US and NL, research has finally come to address the fundamental issues for policy and practice. The novel contribution concerns whether the known improvements in hearing from VTs and other therapeutic effects from adenoidectomy as well as those to hearing, do work through in valued ways to improving lives of children and families. In TARGET, one major innovation has been the systematic determination of what the outcome measurement should comprise. Because of the vulnerability of self-reported and proxy measures to expectancy and halo biases, we have developed and validated a method to adjust for reporting bias in an unblindable trial. This has enabled us to show that behaviour improvements from VTs outlast the tube patency period, and that these are largely **not** due to expectancy bias. However (1) **of the other non-hearing effects from VTs, the majority is due to such bias.** (2) **The improvement in HL from VTs is indeed large, but it is very short-term.** Hearing plus the modest knock-on improvement in behaviour form (3) **a rather narrow set of outcomes** on which to base a policy. Together, these three observations can explain the discrepancy between favourable clinical impression and unimpressive benefits of VTs in controlled trials. In contrast, benefits from adjuvant adenoidectomy, though modest, are more broadly-based, unbiased and lasting. When the healthcare cost-savings from adenoidectomy are further considered, combined VTs + adenoidectomy is 6 to 8 times more cost-effective than VTs alone. It is therefore questionable whether, in the long term, selective targeting of the adjuvant adenoidectomies onto those most able to benefit is required (although contra-indications for safety would still apply). In early implementation, it is only reasonable to expect the adenoidectomy rate to go up from the present ~15% on new cases (ie not reinsertions) to, say, 65% in the relevant age group (> 3.5 years of age). Interim goals are required because even this modest step in the direction of evidence will require delivery systems to adapt considerably. The trial therefore provides an interim evidence-based indicator

to help focussing adjuvant adenoidectomies on those who will benefit, via the OM8-30 short-form impact measure. For VTs alone where adenoidectomy would not be given, a small trial embedded within TARGET, using an extra performance measure of speech identification in noise (now commercially available), provides an indicator of the children who particularly benefit. These two evidence-based indicators have a cogent scientific rationale, and are not post hoc findings.

For reaching an overall policy conclusion, it was necessary to aggregate outcomes measured in 9 domains. The aggregate formula requires explicit weights, equal weighting not necessarily being correct. We have used two systems of importance weights for outcome domains, one based on parents’ frequencies of mention in response to open-ended questions, and one based on the average of ratings from ENT and Public Health doctors. Policy issues change, so these two approaches span two versions of how an answer to the research question can achieve the necessary conviction value. The first views it as needing to resolve the inter-professional conflict of the early 90s, and second views it as necessary to inform parents in a fashion nuanced by their valuations of outcomes, in the light of the contemporary emphasis on patient choice. Would treatment effect sizes change if we weighted outcomes for various other stakeholders such as parents, community doctors in audiology, GPs, or teachers? And are the differences small enough to permit an agreed overall conclusion for all the stakeholders? Parents up-weight, but teachers down-weight the role of hearing relative to ENT and audiology. As hearing comprises nearly all the benefit from VTs, the relatively poor position of VTs alone to VTs plus adenoidectomy described above must assume a better light when the total outcome measure is weighted for the parent’s perspective. But hearing does not well predict the summary of all other outcome measures, and only accounts for 20% of concerns expressed by parents of children with confirmed OME. Community doctors’ high emphasis on behaviour problems in OME must likewise dilute, for them, the general advantage for also performing an adenoidectomy from their viewpoint, as behaviour is not improved by adenoidectomy. However, as regards the absolute advantage for adenoidectomy, its broadly based effects are robust across differences in valuation perspective (ie in weighting profile).

These are only the core treatment and policy findings from TARGET for which it has introduced and demonstrated the viability (particularly via the short-form OM8-30 measure for applying the results) of a truly whole-child perspective. It has produced over 40 findings of which three-quarters remain to be published and generates many practical recommendations on detailed procedures for ENT and audiology. It is hoped to make the rich TARGET database, of which several aspects have not yet been fully exploited, available to the relevant user communities as an aid to teaching and further research.

## Getting the best out of Appraisal

Pablo Foster

**A Your day is about “clinical and professional development”. My contribution is to help you with your professional development and your work-life balance.**

When properly used, *appraisal is a powerful development process*. Too often it is seen as just an administrative exercise or as a top-down managerial exercise of power, so no-one really benefits.

**B** Appraisal works best when the *appraisees drive the process*. After all, they should be the main beneficiaries. They can *collectively* drive the process by, for example:

- 1 **Agreeing Ground Rules with their Trust** – such as:
  - The process is taken seriously and learning plans are honoured.
  - Objectives should be few, focused and regularly revisited.
  - The achievement of outcomes should be properly resourced.
  - The participants should be as honest and positive as possible.
  - Feedback should be two way and supportive, not abusive.
- 2 **Having Personal Development Plans** which are realistic, realisable and supported – by colleagues and by the management.
- 3 **Insisting on the Trust collecting** the monitoring information, supplying the data required by the documentation, and moving towards 360° appraisal.
- 4 **Ensuring that those involved in appraisal are trained**, that the process makes appropriate links with other processes (e.g. Clinical Governance and Business Plans), deals with issues arising from appraisals, and publishes details (albeit anonymous) of the development resources committed.

**C** The basis for your *work-life balance* claims derived from the law, which frames appraisal. Under *Employment Law* (and your ultimate employer is the NHS, even though your contract may be with a Trust), *your employer is responsible* for your:

- safety
- security
- stress levels and health at work.

Within this legal framework, appraisal cannot be used to lower safety standards, increase insecurity or raise levels of stress until they threaten health and peace of mind. However, you can use appraisal to argue for:

- proper resourcing to do your job
- proper support – e.g. training up someone you can delegate to
- flexible working arrangements to accommodate family responsibilities or other work roles.

You have social rights in employment, as well as service obligations. According to the CMO, appraisal is “*an employer-led process to give doctors / consultants feedback on their performance, to chart continuing progress and to identify development needs*”. The forms encourage you to discuss resources and support.

**D** *How do you get feedback on your performance?*

You can move from counting Christmas cards and letters to actively soliciting feedback. The Trust could gather most of it through an *anonymised 360° appraisal* process, through *patient outcome surveys*, etc. Or you could form a team from among the people you work with most frequently and give each other feedback on the basis of agreed ground rules – using the forms provided. The CMO’s starter questions provide a useful entry for such discussions:-

- How good as professions are we? [How do we know?]
- How well do we perform? [Who says? Can we get evidence?]
- How up-to-date are we?
- How well do we operate as a team?
- What are our development needs?
- What are our resource needs?
- How well are we meeting objectives?

**E** *How can you learn?*

If you always do what you’ve always done, you will only get what you’ve always got.

Try new ways. For example, how many of you link up with a *fellow learner*, and share insights, web sites and resources? How many of you try, as a group, *role playing* – e.g. the managing of difficult situations, new skills, like appraisal, new behaviours, with helpful feedback / ideas / suggestions *from peers / colleagues*? How many use *e-learning* – CD ROMs, web sites, chat rooms, etc. How many use the NHS University resources? How many of you jot down new learning in a diary / logbook etc.? How many of you have got a *mentor* –to help you manage your career?

It is worth taking development and appraisal seriously because successful appraisals lubricate successful *revalidation*.

**F** *What you and your employer want from appraisal?*  
[see separate handouts / on-line information]

Both of you will seek to structure the appraisal process by having:

- A schedule of planned outcomes and timed milestones.
- Regular feedback sessions [*not* annual crash meetings].
- Documentary evidence to help with development and *revalidation*.

In some cases you may have to train your employer before a genuine development process evolves. Be patient with them – like you, they are probably distracted by constant busyness. Your future strength lies in mutual collective support, and appraisal is one process for building that. Build on your networking today, and form local support groups.



## **Review of Paediatric Audiology Service Provision**

**Dr Jane Lyons**

**On behalf of the North West Regional Audiology Clinical Audit Group**

### **Compiled by Service Review Subcommittee:**

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The North West Regional Audiology Clinical Audit Group (NWRACAG) commissioned this document on order to help provide a benchmark of service provision against which services can be evaluated.

### **Introduction**

The initial work on this audit was commenced in 2000/2001. Although non-medical staff have benefited from personal development plans for some years, this is only just been implemented for the medical profession. Appraisal for NHS consultants is now mandatory as outlined in the document (AL(MD)5/01). This document specifically mentions that in three areas peer review can be of importance. They are:

- Good medical care
- Working relationship with colleagues
- Relations with patients

The NWRACAG felt it was important there should be a guide for standards in paediatric audiology. Paediatric audiology services are still in an early stage of development, and it is generally accepted that these services are not uniform across the country. It was considered important that this review should be of a whole service, and not just of the consultant or clinical lead.

### **Aims and Objectives**

Service review in this context is an assessment of the quality of work and working conditions within a paediatric audiology service of a Trust, and is carried out by colleagues within the speciality from another area. It is hoped that this will promote uniformity of service provision within the speciality, quality (clinical governance) and ensure delivery of family friendly paediatric audiology services. Therefore it is proposed that two lead clinicians from other services undertake the review after completing an appropriate training programme.

The service review document is intended to be a holistic review of paediatric audiology services. It is not meant to assess individual performance. The ultimate aim is to assess the quality of service received by the end user i.e. the hearing impaired child and its family, by:

- Complementing appraisal and personal development plans
- Providing a means of informing the Trust where there

- are issues affecting the performance of the service
- Recognising and encouraging good practice

### **Guidelines / Standards**

There are no published standards or guidelines for paediatric audiology services, but there are 2 documents that are particularly relevant to this service review:

- The BAAP Policy Document, Audiological Medicine in the UK – a guide for users, commissioners and providers, British Association of Audiological Physicians 2002.
- Competencies in paediatric audiology, British Association of Community Doctors in Audiology, 2002.

### **Results**

The review of paediatric audiology service provision remains is now in its final draft, and is about to be piloted. It has been decided that the service should be reviewed under various categories:

- The service
- Staff
- Facilities – test rooms and accommodation
- Equipment
- Training issues
- Audit and research
- Clinical competence and quality
- Multidisciplinary issues – liaison and communication
- Record keeping

For each of these there is an explanatory paragraph, followed by a list of recommended staff, equipment or services etc. as relevant to the category. The paediatric audiology service under review will be expected to provide evidence, in the form of documents or by inspection, whichever is most appropriate. A final report will be produced, which the Head of Service should forward to senior managers within their Trust as evidence of the quality of their service or to backup any requests for further resources etc. There would be a follow up visit at a later stage to discuss any progress in implementing recommendations.

### **Summary**

As far as the NWRACAG are aware review of paediatric audiology service provision has never been attempted before. The plan over the next year is to conduct a pilot study by reviewing a few selected paediatric audiology services. The results published in next year's audit report.

Government policies such as NHSP and MCHAS have formalised the need for services to set up and develop Children's Hearing Services Working Groups (CHSWGs). To support services in developing multi-agency working practices and involving parents as partners, the NDCS is surveying all Heads of Service for Audiology, and relevant departments in Education and Social Services in relation to CHSWGs. This session provides an update on the aims of the questionnaire and how NDCS plans to support CHSWGs and parental representation in the future.

### WHY A CHSWG QUESTIONNAIRE?

- 1 NDCS CHSWG Project finishes March 2004
  - Evaluation for NDCS / The Healthcare Foundation
- 2 A multi-disciplinary response is required
  - Audiology
  - Education
  - Social Services
- 3 Consultation needed from services
  - What are the issues?
  - How can these be tackled?
  - What support is required?
  - How can CHSWGs be made effective and sustainable?
4. Establish areas of good practice to share with CHSWGs throughout the country.

### CHSWG ISSUES

- 1 **Historical**
  - Groups developed from the Quality Standards in Audiology as AWGS / PAWGs
  - Introduction of NHSP and the Quality Standards In The Early Years has required a change of focus to multi-disciplinary

- Many groups are still effectively AWGs with the name of CHSWG

### 2 **Structural**

- Government focus – multi-disciplinary / patient focussed / family led
- Funding / structures / policies not yet filtered into ground level practice

### 3 **Personal**

- Changing life-long working practices
- “Them and us” situation

### WHY HAVE CHSWGs?

1. Multi-disciplinary working will continue to be on the agenda
2. The many benefits of multi-agency working
  - Improved communication between disciplines
  - Improved understanding
  - Reduction in duplication
  - Identification of gaps
  - Access to additional resources

### AIMS OF THE CHSWG QUESTIONNAIRE

1. Disseminate information of good practice to reduce duplication at a national level
2. Develop CHSWG models to assist groups
3. Develop information to allow NDCS to lobby Government in support for services
4. Raise awareness of CHSWG within services and at senior level
5. Develop continued support for parents and services in the correct manner, i.e. training for parents

## *Electing Parents to a Children's Hearing Services Working Group Keith Stewart, Associate Specialist, East Kent Children's Hearing Service*

### **Introduction:**

Paediatric Audiology Working Groups (PAWG) have existed for many years throughout the United Kingdom. More recently, in line with "family friendly" children's audiology they were renamed Children's Hearing Services Working Groups (CHSWG) and moved away from a largely medical and educational model to a parent centred one. This move was brought about by the NDCS (2000) Quality Standards in Paediatric Audiology IV<sup>1</sup> and the national move towards universal newborn hearing screening.

During 2002 it became obvious that the invited parental representatives on the East Kent PAWG were having a more onerous task as the organisation moved up a gear prior to the implementation of the newborn hearing screening programme (NHSP). A democratic election to bring forward six parental representatives to the East Kent CHSWG was planned, executed and the successful candidates have worked as equal members of the CHSWG and taken a key part in the Standards and Audit, and the Family Friendly sub-groups of the CHSWG.

### **Method:**

Tools:

- Up to date, verified, unified list of hearing impaired children in the East Kent (Health) catchment area.
- A mail-merge facility.
- A central venue for hustings and voting to take place.

The unified list of hearing impaired children resident in East Kent and shared between Health and Education was verified and most recent addresses checked against the paediatric audiology database. All parents/main carers were circulated using a mail-merge programme from the PARS record system. The letter (Appendix A) explained about the purpose of the election, asked all interested parents/carers to declare their interest and invited those interested to attend a meeting. The letter included a return slip to indicate interest in standing for election and each slip was tagged to the name and date of birth of the child of the parent/carer.

An evening meeting was held at which parents/carers attended or were represented by proxy and had up to five minutes to address those attending or have their addresses read out. The names of all those expressing an interest in standing for election were entered on a prepared ballot sheet. The names of those deciding not to stand were struck out and the names of those still wishing to stand were retained. A ballot was held.

Six parental representatives were elected to the East Kent CHSWG.

### **Results:**

The Kent-wide unified list of hearing impaired children had only been completed and verified in September 2002 so most of the data was up to date. It was possible through the PARS database to separate all those children living within the East Kent Hospitals' NHS Trust catchment area: this included some, but not all, children within the Kent County Council East- and Mid-Kent areas. The mail merge of some 284 children's parents/carers was achieved and the letter and reply slip included in a window envelope. The staff at Kent Paediatric Audiology Service had been fully briefed about the proposed democratic elections and was able to field simple questions. Some parents/carers wished to discuss their candidature or the wider work of the CHSWG with the author and such discussions were by telephone.

Thirty-eight parents/carers expressed an interest in standing for election and 21 arrived, at a central venue in East Kent, for the meeting on a very frosty evening in January. Initially all those attending and four others wanted to stand. Three parents/carers decided, after listening to the others speak and speaking themselves, that they no longer wished to be considered for election. A second ballot had to be held for the last two places as there were four candidates (scoring equally on the first ballot) for those places.

Six parents were elected and have represented the whole body of parents/carers of deaf children in East Kent, both on the CHSWG, but also on sub-groups dealing with Family Friendly and Standards and Audit matters to do with the NHSP.

### **Discussion:**

The East Kent PAWG had grown from a small group of clinicians who started an "at risk" hearing screen in 1995 into a multi-disciplinary CHSWG from Health, Education, Social Services and the voluntary sector with one, invited, parental representative. Two other parents had been co-opted but it was felt that a transparent, democratic election from among the parents/carers of all deaf children in East Kent was the appropriate way forward. The completion of the first unified list of deaf children was driven by the ability to use it for such exercises. As a spin off from the mail-shot we were able to correct a few addresses and many telephone numbers. We discovered that some children had moved out of the county; unknown to education or health. Democratic

election of parental representatives is not a costly exercise but funding is not identified within service budgets. Postage, stationery and secretarial time cost less than £1 per parent/carer contacted. It raised the profile of paediatric audiology and of the CHSWG.

The date of the evening meeting clashed with a parental group taking their children to the panto, so a few parents/carers were unable to attend, but they gave the author short presentations that he read out at the hustings. Sadly none of those unable to attend was elected to the CHSWG, demonstrating a weakness in the process.

Whilst the presence of six representatives on the CHSWG has meant that the average meeting now has thirty people attending, the parents/carers have had influence, given useful opinions and represented the views of other parents/carers. They have provided valuable input to the sub-groups and once the NHSP is running (postponed twice by DoH due to lack of funds to train the screeners), they will be invited to join sub-groups looking into wider aspects of children's hearing services. Parental/carer representatives have been offered the NDCS CHSWG training and some parents have taken this up. Their existence as an elected group of parents/carers empowers them to offer representation to a wider church on behalf of all parents/carers of deaf children, locally.

## Conclusions:

Parental representation on CHSWGs is essential. The cosy, co-opted representative is unlikely to be effective. Sufficient representatives, to not be daunted by all the professionals on the CHSWG, are important. A unified list of all deaf children is obligatory and most services should already have this. The exercise increased the profile of the East Kent service and parents/carers now communicate more readily with the service and the author.

A parent/carer chair of the CHSWG would be the icing on the cake.

## Reference:

<sup>1</sup> NDCS (2000), London: Quality Standards in Paediatric Audiology Vol. IV, *Guidelines for the Early Identification and the Audiological Management of Children with Hearing Loss*

## Acknowledgments:

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## Appendix A

Dear Parent or Main Carer

## EAST KENT CHILDREN'S HEARING SERVICES WORKING GROUP

We are writing to ask you if you would like to become a **Parental Representative** of the East Kent Children's Hearing Services Working Group (EK CHSWG)? If you are not keen to do this yourself, do you want to suggest someone else?

The EK CHSWG has been formed to advise on bringing in a new hearing test in East Kent. It is called "Newborn Hearing Screening Programme" or NHSP and should start sometime in 2003. Most newborn babies will have a test in hospital in the first few hours after birth.

With your experience of *Child's Name's* hearing problems, your opinion and advice would be very useful to those people from the NHS, Education and the Social Services who already make up the EK CHSWG.

## What does it involve?

- Attending two or three meetings per year
- Giving advice to the committee from your experiences as a parent with a hearing impaired child
- Helping to check how well children with hearing problems are supported and helped by the local NHS, Education and Social Services
- Keeping in touch with other parents of children with hearing problems and putting forward their comments at meetings

## Can I get training and support?

Yes the NDCS has a training scheme and the co-ordinator is Rosie Lloyd [rosie@ndcs.org.uk](mailto:rosie@ndcs.org.uk)

A meeting of parents is at 6pm, on Thursday, 9<sup>th</sup> January, at Canterbury Health Centre, Old Dover Road, Canterbury. Please come along to find out more and vote for up to six Parental Representatives.

We would appreciate it if you could complete the attached form and return it to Dr. Keith Stewart. Directions for the Canterbury Health Centre will then be sent on to you.

Thank you for your time and with best wishes.

Keith Stewart. February 2004 .

# *ADVENTS*

*Actual Sentences Found on Patients' Hospital Charts (Proves that those medical folks are right on top of things. When you're pushed for time, it is so easy to write a note and not take the time to re-read and correct.)*

- 1. She has no rigors or shaking chills, but her husband states that she was very hot in bed last night.*
- 2. Patient has chest pain if she lies on her left side for over a year.*
- 3. On the second day the knee was better, and on the third day it disappeared.*
- 4. The patient is tearful and crying constantly. She also appears to be depressed.*
- 5. The patient has been depressed since she began seeing me in 1993.*
- 6. Discharge status: Alive but without my permission.*
- 7. Healthy appearing decrepit 69 year old male, mentally alert but forgetful.*
- 8. The patient refused autopsy.*
- 9. The patient has no previous history of suicides.*
- 10. The patient has left white blood cells at another hospital.*
- 11. Patient's medical history has been remarkably insignificant, with only 40 pound weight gain in the past three days.*
- 12. Patient had waffles for breakfast and anorexia for lunch.*
- 13. Between you and me, we ought to be able to get this lady pregnant.*
- 14. Since she can't get pregnant with her husband, I thought you might like to work her up.*
- 15. She is numb from her toes down.*
- 16. While in ER, she was examined, X-rated and sent home.*
- 17. The skin was moist and dry.*
- 18. Occasional, constant infrequent headaches.*

*Sent in By Dr Sarita Fonseca*