



**TRUSTEES' REPORT  
EXTRACTS - YEAR TO 30 SEPTEMBER 2004**

**Significant events**

The following is a report of the work of Dr Susan Hall who was funded by a grant from the Foundation over the period under review. The grant holder is Professor David Hall of the School of Health and Related Research, Sheffield University. In the narration which follows the \* indicates grant-aided activity. The report also covers some other scientific activities of the Foundation since these are related to Dr Hall's (unremunerated) position as Chair of its Medical and Scientific Advisory Board until January 2004.

**1. Epidemiological surveillance of Reye's Syndrome (RS) and related scientific matters\***

**Cases of RS reported**

As noted in last year's report, surveillance of RS via the British Paediatric Surveillance Unit ceased in April 2001. However, the arrangements with The Office of National Statistics and The General Register Offices of Northern Ireland and Scotland continued to be maintained throughout the year. Under these, the Offices sent Dr Hall copies of all death entries where RS was mentioned as a cause of death, whatever the age of the subject.

In the year 1 October 2003 to 30 September 2004, no RS deaths were reported from Scotland or Northern Ireland; for England there were two deaths - a 21 year old woman who had had an illness diagnosed as RS when she was 4 months old which left her with severe brain damage, the complications of which were the cause of death; and a girl aged 2 years 9 months for whom the cause of death was recorded as "Reyes-like syndrome".

**2. Professional education - Workshop on RS and Reye-like inherited metabolic disorders \***

The background, preliminary plans for, and report on this Workshop were outlined in all the previous annual reports between 1999/2000 and 2002/2003. In summary, its purpose was to bring together epidemiological, clinical, biochemical and pathologist experts in the field of RS and RS-like illness to discuss issues of diagnosis and management which would lead to development of an educational package or formal clinical guideline for front line accident and emergency doctors, paediatricians and intensivists. This would include a contribution to the Advanced Paediatric Life Support (APLS) course and manual which is taken by all UK paediatricians in training.

The previous annual report to trustees referred to a grant application from the Division of Child Health at Queen's Medical Centre, Nottingham, which had been stimulated by the Workshop. Its purpose was to develop a formal evidence-based guideline for the diagnosis, investigation, and management of acute encephalopathy, including RS and metabolic disorders presenting as Reye-like illness in childhood. A Research Fellow (Dr Richard Bowker) was appointed and the two year project began in November 2003.

Following the Workshop, Professor David Hall and Dr Susan Hall submitted a grant application to the National Reye's Syndrome Foundation for an extension to their previous grant. This was to enable Dr Hall to:



## 2. Professional education – Workshop on RS and Reye-like inherited metabolic disorders\* (continued)

- i) prepare a report on the proceedings of the Workshop based on the edited transcript.
- ii) prepare a report for publication, on 20 years of epidemiological surveillance of RS in the UK and Ireland and maintain ongoing surveillance of RS via death entries (v.s.).
- iii) implement permanent storage of the RS database.

After external refereeing, the grant of £11,600 was awarded. It was intended to cover Dr Hall's work (part-time - 1.1/2 sessions per week on average) on these projects between 1 June 2002 and 31 May 2003; this was subsequently found to be an over-optimistic estimate of the time required and, with the agreement of the trustees, was extended *without alteration to the size of the grant* to 31 May 2004.

In August 2004 Professor and Dr Hall submitted an application to the Foundation for an extension to the grant, of £750, specifically to cover the service and data handling charge which the Office for National Statistics had introduced for the first time in October 2002 and which was therefore not budgeted for in the original grant application. This sum was estimated to cover the period up to December 2005. At the same time a further extension of the original timescale, to December 2005, was requested, again without any alteration to the original grant.

*During the year under review*, Dr Hall finalised the preparation of the Workshop Proceedings for publication on the Foundation's website. This was a substantial exercise which involved editing nearly 300 pages of transcript of the recording of the meeting (oral presentations plus extensive discussion sessions). The Proceedings were in nine parts and as the draft of each was completed it was circulated to all participants for comment. A second draft incorporating all the comments was then undertaken. A copy of this second draft was sent to the Nottingham Research Fellow (see above) in October 2003 in order to provide an informative background to the Guideline project. The full Proceedings were posted to the website in June 2004 and work began on an executive summary.

To publicise the Proceedings Dr Hall wrote an article for the Royal College of Paediatrics and Child Health (RCPCH) Newsletter which was published in September 2004.

During the year Dr Hall also initiated the process of implementing the Workshop participants' recommendations for modification of the APLS course and manual. This was done in collaboration with the course organisers (the Advanced Life Support Group) and clinical colleagues. It was a timely initiative as the manual was at the time scheduled for updating.

She also assisted with the Guideline project by commenting on various papers and on a parent questionnaire.



### **3. Advisory scientific and medical support for the National Reye's Syndrome Foundation**

Over the period under review, Dr Hall advised Mr Gordon Denney, the Honorary Administrator on a number of issues. However, she retired from the Chairmanship of the Medical and Scientific Advisory Board in January 2004. Support included help with responses to medical queries from members of the public and assistance with an update of the Foundation's website. She also identified misinformation about aspirin use in children on a health site on the web and in the BUPA Newsletter and contacted the appropriate sources to correct this. In addition, regular literature searches for new articles on RS were undertaken and the Hon. Administrator informed about any of interest.

Dr Hall is also asked from time to time to referee articles on RS submitted in scientific journals. She also kept the Hon. Administrator informed about progress with a chapter on Aspirin and Reye's Syndrome written by her and Dr John Glasgow for a book entitled "Aspirin and Related Drugs" under the editorship of K.D. Rainsford. This was published in September 2004.

Submitted by

Dr/ Susan Hall MSc, FRCP, FFPHM, FRCPCH

### **4. Development of a national guideline for the management of children with a reduced conscious level**

The following is *a statement by Dr Richard Bowker, Clinical Research Fellow, University of Nottingham.*

As a direct result of the workshop on Reye's syndrome and Reye-like illnesses held at Doncaster in March 2002, a new project was funded by the National Reye's Syndrome Foundation commencing November 2003. The project will produce a national clinical guideline for the management of children with a reduced conscious level.

Many children with Reye's syndrome or Reye-like illness present to hospital with reduced consciousness or coma. Unfortunately as several other more common conditions present in childhood with reduced consciousness, the diagnosis of rare metabolic conditions is often overlooked. This inevitably leads to delay in diagnosis and treatment which can increase the risk of death or long term disability. Developing a guideline based on an easily recognisable problem (i.e. reduced consciousness) should allow junior staff to manage both the common and rare conditions without the need for initial diagnostic skills.

In November 2003, Dr Richard Bowker, a paediatrician in training, was appointed to develop the guideline over two years along with Professor Terence Stephenson, who has produced several national guidelines for children. During the first 18 months, Dr Bowker has brought together a national panel of experts - the guideline development group - to help produce the guideline. He has completed a thorough search of the scientific



#### **4. Development of a national guideline for the management of children with a reduced conscious level (continued)**

literature to ensure that the recommendations are evidence-based. The formal consensus process to fill in the gaps where the evidence is lacking, has now been completed. The recommendations are nearing their final draft stage and several simple algorithms for use by doctors and nurses have been developed and are about to be piloted.

Many parents have also been involved in the project, helping the panel of experts to understand what parents and patients expect of the health service when they bring a child to hospital with a reduced conscious level. Dr Bowker and the guideline development group would like to take this opportunity to thank all those who have been involved. Before the final guideline has been published, a parent information leaflet will be drafted. This will be piloted on parents and patients before being published, so your help with this will be greatly appreciated also.

The guideline will be published towards the end of 2005. An external appraisal process by the RCPCH will take place, after which time the guideline will be available for all paediatricians and emergency department staff to use when children present to them with a reduced level of consciousness. This should improve the rapid access to the best treatments available.

For further details on the production of the guideline, there is a website which can be accessed at <http://www.nottingham.ac.uk/paediatric-guideline>

#### **5. Resignation of Dr Susan Hall as Chair of the Foundation's Medical and Scientific Advisory Board (MSAB)**

A letter was received from Dr Susan Hall in January 2004 resigning from the position of trustee as she was no longer chair of the MSAB. Her letter of resignation was received by the Board with profound regret. The Board placed on record her considerable achievements particularly in the field of aspirin and RS. She was also the driving force which led to the holding of the Workshop on RS and Reye-like inherited metabolic disorders in March 2002. The results of this successful Workshop are now published on the Foundation's website. The Board of Trustees in recognition of *Dr Susan Hall's outstanding achievements* marked the occasion by making a presentation to her.

#### **6. Appointment of Dr John Glasgow as Chair of the Foundation's Medical and Scientific Advisory Board (MSAB)**

The Board *welcomes* Dr John Glasgow BSc, MD, FRCPCH, FRCP, FRCP(I), FFAEM, DCH as trustee, and chair of the MSAB in succession to Dr Hall.