



**TRUSTEES REPORT
EXTRACTS – 30 SEPTEMBER 2006**

Significant events

The following is a report of the work of Dr Susan Hall who was funded by a grant from the Foundation for the first three months of the period under review. The grant holder was Professor David Hall of the School of Health and Related Research, Sheffield University, who returned the unused balance of the grant to the University who in turn refunded it to the Foundation. In the narration which follows the * indicates grant-aided activities.

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

Cases of RS Reported

As noted in previous reports, 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 until the end of 2005. 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 quarter 1 October to 31 December 2005, no RS deaths were reported from England and Wales, Scotland or Northern Ireland.

Preparation of final report on 20 years of RS surveillance

Work on this continued in the year under review.

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

The background, preliminary plans for, and report on this Workshop were described in previous Annual Reports 1999/2000 through to 2003/2004. In summary, its purpose was to bring together epidemiological, clinical, biochemical and pathologist experts in the field of RS and Reye-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.

The Workshop's main recommendation was that there should be 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. The 2003/2004 Annual Report to trustees referred to a grant application from the Division of Child Health at the Queen's Medical Centre, Nottingham to undertake this and reported that a Research Fellow had been appointed. The two year project began in November 2003.



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

In October 2005 an Open Day, organised by the Research Fellow was held at the Queen's Medical Centre University of Nottingham, in order to present the draft guideline to stakeholders and other relevant parties. Dr Hall attended this. The final guideline was officially launched at the Annual Scientific Meeting of the Royal College of Paediatrics and Child Health in March 2006.

This concludes the report of Dr Susan Hall.

3. Development of a national guideline for the management of children with a decreased conscious level

The following is a statement by Prof. Terence Stephenson, Dean, Faculty of Medicine and Health Sciences, The Medical School, Queen's Medical Centre, Nottingham.

- the patient information leaflet has been translated into four foreign languages.
- A Public Open Day was held on 7 October 2005.
- Key recommendations from the guideline were sent out to the entire membership of the RCPCH as part of the College's process of guideline appraisal in November 2005.
- The guideline was presented to the British Paediatric Neurologists Association in January 2006 (Bristol).
- The guideline was presented to the Royal College of Paediatrics & Child Health in April 2006 (York).
- An external appraisal process by the Royal College of Paediatrics & Child Health took place as promised in a previous report. The RCPCH Quality of Practice Committee appraised the guideline and subsequently the algorithm was disseminated nationally.
- Copies of the guideline, including a DVD of how to use and implement it, have been sent to all A & E departments and paediatric assessment units in the UK and Eire.
- An article reviewing the management of decreased conscious level in children has been published by the journal Current Paediatrics. (Bowker R, Stephenson T) - The management of children presenting with decreased conscious level. Current Paediatrics 2006; 16 328-335).
- A review article highlighting the guideline has been published by the journal Archives of Disease in Childhood which is sent to every member of the RCPCH (effectively every practising paediatrician in the UK and Ireland beyond Senior House Officer level) (Bowker R, Stephenson T, Baumer H.- Evidence-based guideline for the management of decreased conscious



level. *Arch. Dis. Child. Ed. Pract.* 2006; 91:ep115-ep122).

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

- We have also been involved in updating the page on metabolic coma in the latest UK Advanced Paediatric Life Support manual. (Mackaway-Jones K et al. *Advanced Paediatric Life Support: the practical approach*. 4th Ed 2005. Blackwell Publishing)
- The full guideline is available online from www.nottingham.ac.uk/paediatric-guideline
- The guideline was also presented at two BMJ Paediatric Master-classes in September and November 2006.
- The RCPCH is submitting an application to the Foundation for an audit of the guideline, including the dissemination process.

This concludes the report of Prof. Terence Stephenson.

At this point it is appropriate to *place on record* that a number of the Foundation's trustees and a parental representative attended the Public Open Day in Nottingham and that Clifford and his wife Audrey, kindly wrote an account of the proceedings which was incorporated into a newsletter circulated to supporters in September 2006.

4. Statement by Dr John Glasgow

The following is a report by Dr John Glasgow, Chairman of the Medical and Scientific Advisory Board.

a) Public Open Day

I was pleased to attend the Public Open Day on 7 October 2005 at the University of Nottingham. This was an opportunity to attend the launch of an Evidence-based Guideline developed by a team lead by Prof. Terence Stephenson at the Department of Paediatrics on the "Management of the Child and Reduced Consciousness". Dr Richard Bowker was the Research Fellow most closely involved. As well as the presence of a number of trustees on that occasion it was good to meet again with someone's own erstwhile collaborators most especially Drs. Susan Hall and Bruce Middleton.

b) Paper "Reye's Syndrome – The case for a causal link with aspirin"

I fulfilled an invitation to publish a response to a paper published in 2002 suggesting that there was no link between aspirin usage and Reye's syndrome. The reference to our paper is "*Reye's Syndrome – The case for a causal link with aspirin.*" It appeared in *Drug Safety 29 (12): 1111-1121, 2006*. This reviews the considerable weight of evidence accumulated over 25 years that an aspirin associated encephalopathy is a definite clinical syndrome. The work carries an acknowledgement of the support received from the Foundation over many years.

c) The Foundation's website



**National Reyes Syndrome
Foundation UK**

Together with the Hon. Administrator I have been reviewing the Foundation's website with a view to its enhancement.

4. Statement by Dr John Glasgow (continued)

d) Advisory Scientific and Medical Support for the National Reye's Syndrome Foundation

Over the period under review, I have liaised and advised the Hon. Administrator on a number of issues both medical and scientific.

This concludes the report of Dr. John Glasgow