



**TRUSTEES REPORT
EXTRACTS – YEAR TO 30 SEPTEMBER 2005**

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 a 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 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 2004 to 30 September 2005, no deaths were reported from England and Wales, Scotland or Northern Ireland. *This is the first 12 month period with no deaths recorded as being caused by RS since surveillance began in 1981.*

Preparation of final report on 20 years of RS surveillance

As a preliminary to this it has been necessary to verify the data entered on the computer records over the last 5 years of the surveillance scheme in order to check for errors and reconcile the data base with the paper records. This was completed in the period under review.

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

The background, preliminary plans for, and report on this Workshop were described in previous Annual Reports for each of the years commencing 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 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.



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

The previous Annual Report to trustees referred to the Workshop Full Proceedings, which had been published on the Foundation's website during that year. It also referred to the fact that work had just begun on preparing an Executive Summary which would also summarise the action points made by the Workshop participants. The Summary was completed in March 2005 and posted on the website. Each action point was then addressed for example:

One of the most important was the need to raise awareness among policy makers, the profession and the public of the possibility of RS re-emerging in the predicted influenza pandemic if people either self medicated with aspirin or the warning labelling was forgotten or ignored. The existing draft advice to the public from the Department of Health did not contain a reminder about aspirin use in children and the Pandemic Plan itself made no reference to RS. Dr Hall prepared a paper which was submitted to the Department of Health which resulted in the revised version of the Pandemic Plan containing a substantial section on RS and the leaflets for the public now include the warning.

Another Workshop recommendation was the Advanced Paediatric Life Support course manual should be updated with regard to RS and Reye-like inherited metabolic disorders. The new manual was published in January 2005 and did contain the recommended amendments; this is important because most paediatricians in training will take the course.

A survey of clinical chemistry laboratories regarding the use of post mortem bile in the diagnosis of inherited metabolic disorders was undertaken by Professor Anne Green following a request for further information by Dr Hall; this had been recommended at the Workshop. Usage was patchy and its value is to be further explored via the National Metabolic Biochemistry Network.

Information on progress with recommendations on training paediatricians in IMD's and on service provision, made at the Workshop (e.g. CPD credited courses, development of national standards), was sought from Dr Mike Champion, who reported good progress on all the recommendations made.

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 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.

In the year under review the Guideline was nearing completion and Dr Hall liaised frequently with the Research Fellow to ensure that it encompassed all the recommendations that had been made at the Workshop. She also participated in the consultation aspect of the Guideline development process by commenting on drafts of the proposed clinical algorithm.



3. Advisory Scientific and Medical Support for the National Reye's Syndrome Foundation.

Over the period under review, Dr Hall advised the honorary administrator on a number of issues, both scientific and administrative.

4. Publications*

In the period under review Dr Hall submitted two letters to Archives of Disease in Childhood in response to articles published in that journal, one of which failed to mention RS in a review of the burden of illness caused by influenza, while the other promulgated a misconception about the association with aspirin. Both letters were published in the e-correspondence section of the journal.

This *concludes* the report of Dr Susan Hall.

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Also on the subject of Publications, is a *statement by Dr John Glasgow*, Chairman of the Foundation's Medical and Scientific Advisory Board

This report is with reference to the publication "*Aspirin and Related Drugs*" edited by *KD Rainsford* which included a chapter (chapter 9) on the subject of Reye's Syndrome and Aspirin by *JFT Glasgow* and *SM Hall*, CRC Press 2004, pages 555-585.

This was an exhaustive review focusing particularly on epidemiology and causation, in a weighty tome published to mark the aspirin centenary although it came out a little late.

5. Development of a national guideline for the management of children with a reduced conscious level.

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

- The guideline was delivered on time
- A Public Open Day was held on 7 October 2005
- The patient information leaflet has been translated into four foreign languages
- The guideline was presented to the British Paediatric Neurologists Association in January 2006
- The guideline was presented to the Royal College of Paediatrics & Child Health in April 2006 (York)



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

- An external appraisal process by the Royal College of Paediatrics & Child Health took place as promised in the 2004 Annual Report. The RCPCH Quality of Practice Committee has now appraised the guideline and so it is the right time to disseminate the algorithm nationally
- We have a list of paediatric clinical directors provided by the RCPCH Quality of Practice Committee and a list of Accident & Emergency Department leads for England, Wales and Scotland. We propose to send these a copy of the guideline with a covering note to encourage implementation of the guideline. There are 800 addresses in total.
- The Quality of Practice Committee will be sending out the first of the two attached documents in August 2006 to every member of the RCPCH. This should again help raise awareness of the guideline.
- An article reviewing the management of decreased conscious level in children has been accepted for publication by the journal Current Paediatrics.
- A review article highlighting the guideline has been accepted by the journal Archives of Disease in Childhood which is sent to every member of the RCPCH (effectively every practising paediatrician in the UK beyond Senior House Officer level).
- We have also been involved in updating the page on metabolic coma in the latest UK Advanced Paediatric Life Support manual.

The future of the Foundation

In the report for 2003/2004 the trustees stated that they had been carefully considering the future direction of the Foundation. This had included a number of options that might be available to them, bearing in mind the need to preserve the future identity of the charity if at all possible. This had led them to consider the benefits of incorporating the Foundation into a larger organisation. As also indicated in the 2003/2004 report, the hon. administrator had been in correspondence with the Charity Commissioners on a number of issues, and these had included matters relating to corporate trusteeship.

The reasons the trustees have had to give serious consideration to these issues are as follows:

- a) the hon. administrator and the trustees are at or well beyond retirement age.
- b) the removal of aspirin from the market for children (other than for specific indications) has resulted in the virtual disappearance of 'classic RS'.



The future of the Foundation (continued)

- c) the trustees still receive enquiries from parents of children where RS has been considered, though often the final diagnosis is an inherited metabolic disorder.
- d) the pathogenesis of RS is not fully understood and it could re-emerge, particularly in older teenagers or even in adults, if there were to be a major pandemic of influenza.

On 19 October 2004 a meeting took place between Mr Len Tyler, the secretary of the Royal College of Paediatrics and Child Health (RCPCH) and the hon. administrator to ascertain whether the College would be prepared to become a corporate trustee of the National Reye's Syndrome Foundation of the UK. The principle was in due course accepted by the Executive Committee of the College. Subsequently the matter was placed before the Council of the RCPCH on 6 July 2005 when the following *resolution* was passed viz: -

Minute C/05/35 –Council

- d) "Considered a report on the National Reye's Syndrome Foundation. Council AGREED that the College should become a Corporate Trustee of the NRSF, at a time to be agreed between the Honorary Administrator of the NRSF and the Secretary of the RCPCH and subject to the further comments that the Charity Commissioners may have"

The trustees wish to express their appreciation to members of the Council for the help given.