



**TRUSTEE REPORT
EXTRACTS – 30 SEPTEMBER 1987**

Significant events

1. Surveillance of Reye's syndrome

There has been a *reduction* in the number of cases of Reye's syndrome in the United Kingdom compared with previous years. This is a most welcome trend : however the trustees would wish to reserve comment until a definite pattern emerges with the passing of time. In the meantime the Foundation must persist in the vigilance of being ever watchful on the sale of all aspirin products to ensure they are clearly labelled with a warning not to give to children except on the advice of a doctor.

2. Medical Research

The Foundation is now in a position to make a significant contribution to assist in the work of medical research into Reye's syndrome. The trustees wish to thank parents, organisations and charitable trusts who have made this achievement possible. The trustees' appeal for continued support, in order that their target of £200,000 can be achieved and enable much needed medical research to continue.



APPENDIX
BRITISH PAEDIATRIC SURVEILLANCE UNIT
2nd ANNUAL REPORT
1986/87

Abridged

Conditions studied:-

Reye's syndrome

Kawasaki disease

Haemolytic uraemic syndrome (HUS)

Haemorrhagic shock encephalopathy syndrome (HSES)

Reporting of these conditions has enabled the effectiveness of the BPSU's 'active' method of case ascertainment to be measured by comparing numbers of reports received with those received during the preceding three-four years when a "passive" method was employed. There was a dramatic increase in reporting of Kawasaki disease – numbers in 1986 rose steeply in the second half of the year to reach an annual total of 77 compared to 32, 16 and 17 in 1983, 1984 and 1985 respectively. A similar increase occurred in HUS reports – 114 in 1986 compared to 31, 46 and 85 in 1983-85.

There was also an apparent increase in *Reye's syndrome* reports which was disappointing because it immediately followed immediately after the warning concerning a possible association with aspirin issued by the Committee on Safety of Medicines in June 1986. Detailed analysis, however, showed that some of these cases were children whose onsets were before June 1986, some were duplicate reports and some were patients who subsequently had their diagnosis revised. In fact the *Reye's syndrome* surveillance scheme has shown that, in spite of a better method of case ascertainment, *numbers since June 1986 have been lower* than ever recorded before. It has therefore been an important measure of the effectiveness of a public health preventive intervention.

In contrast to the other three conditions, reports of HSES did not increase following introduction of the BPSU. Numbers were greatest in 1982 and 1983 and had been declining in 1984-87. It could therefore be surmised that some unusual exogenous agent associated with HSES was particularly prevalent in the early 1980's but has since declined.

Dr Susan Hall (PHLS CDSC)

Cases Reported

Ascertainment of cases has continued to show a marked improvement on previous, "passive" surveillance systems. The system is now functioning smoothly and offers a more consistently effective means of case ascertainment than any currently available alternative method.

The two main weaknesses which have been found in the reporting scheme are the anonymity of cases and its unsuitability for conditions which have to be reported immediately. The anonymity of cases reported can entail extra work for the reporting paediatrician in tracing casenotes and for the investigator in ensuring that there is no duplication in their database or register. The report card has been redesigned in an attempt to overcome this problem. The monthly cycle of the system makes it less suited to collection of immediate information, for instance about a local outbreak of a disease.



Table 1

Table 1 shows the number of cases reported for each condition in each quarter of the first fifteen months of reporting (June 1986-August 1987). A dash (" - ") indicates that the study concerned was not in progress in the relevant month. In each column the figure under "A" is the total number of reports received and the figure under "B" is the corrected figure excluding cases not yet followed up, those reported in error and those double-reported within the BPSU system.

Table 1 – Cases reported
by quarter – for the 15 months June 1986 to August 1987

Condition	1 st Qtr Jun-Aug		2 nd Qtr Sep-Nov		3 rd Qtr Dec-Feb		4 th Qtr Mar-May		5 th Qtr Jun-Aug		TOTAL	
	A	B	A	B	A	B	A	B	A	B	A	B
AIDS	14*	7	9	6	6	3	8	5	7	1	44	22
Herpes	7*	6	8	2	2	0	4	1	9	5	30	14
Reye's	15	10	16	5	12	3	6	2	7	5	56	25
Kawasaki	33	30	36	31	29	22	25	21	28	19	151	123
HUS	20	18	13	11	6	4	12	7	23	8	74	48
HSES	2	2	2	2	9	7	4	1	3	0	20	12
SSPE	9*	8	14	11	2	1	8	6	9	7	42	33
X-LAED	13	2	-	-	-	-	-	-	-	-	13	2
Lowe	-	-	-	-	11	5	4	0	0	0	15	5
ALL	113	83	98	68	77	45	71	43	86	45	445	284

A: All reports received

B: Cases confirmed at 31/12/87

* First quarter includes all cases known, or seen in last 12 months

When a case is followed up by the appropriate research worker, it may be confirmed or found to be a duplicate report or an error. The most common reason for a case not to be confirmed is because the original diagnosis is revised; this has occurred most often in cases of *Reye's syndrome* and neonatal herpes.

SSPE = subacute sclerosing panencephalitis

X-LAED = X-linked anhidrotic ectodermal dysplasia

Lowe = Lowe syndrome