

An analysis of available statistics from the Registrar General's Statistical Review of England & Wales for 1966, from figures supplied by the General Register Office, and by the relevant Departments in Scotland and Northern Ireland.

N.B. The term SB used includes throughout both Spina Bifida and/or Hydrocephalus cases.

1. INCIDENCE.

The total number of babies notified as born with spina bifida and/or hydrocephalus - in a letter from the General Register Office dated January 17th, 1968 - is

2,130

In quoting this figure, the Medical Statistician says "We suspect this is an underestimate".

2. The total of 2,130 represents 2.47 per 1,000, or 0.247% of total births, which numbered 863,066.

3. STILLBIRTHS

Total Stillbirths	-	13,243	
Total Stillbirths due to congenital malformation of foetus	-	2,464	= 0.29% of total births = 18.6 % of all still-births
SB Stillbirths	-	667	= 0.08% of total births = 5.0 % of all still-births = 27.1 % of all still-births due to congenital malformation of foetus.

4. Previous years' SB stillbirths were as follows:-

1961	972	1964	736
1962	838	1965	670
1963	803	1966	667

The 1966 total is 68% of that of 1961, showing a 32% reduction over six years.

5. DEATHS, SURVIVAL RATES

Numbers of deaths are taken from the Statistical Review.

Percentages of deaths and survival rates are based on the assumptions that:

- The actual incidence of SB births is 2,130
- That total SB live births number 1,463
- That those children who died in 1966 under 1 year old were born in 1966, those 1 year old were born in 1965, 2 years old in 1964, 3 years old in 1963, and 4 years old in 1962.

This can not be deduced from the Statistical Review as, e.g. a child who died in 1966 aged 9 months could have been born in either 1965 or 1966. For the purpose of the following table, it is assumed that these differences would cancel themselves out.

6. Total deaths under five years of age - 18,930
 Total deaths under five years of age
 due to congenital malformations - 3,605 = 19% of above
 Total SB deaths under five years of
 age - 767 = 4.0% of
 total deaths
 under 5
 = 21.0% of all
 deaths under
 5 due to
 congenital
 malformations
7. SB deaths over five years of age totalled 48, making a total of 815.

	<u>SB deaths</u>			<u>SB Survival Rates</u>	
	<u>No.</u>	<u>% Total SB Births</u>	<u>% SB Live Births</u>	<u>% Total SB Births</u>	<u>% SB Live Births</u>
Stillbirths	667	31.3	-	68.7	-
Under 1 year	694	32.6	47.4	36.2	52.6
1 year	45	2.1	3.0	34.1	49.6
2 years	12	0.56	0.8	33.54	41.6
3 years	8	0.38	0.55	33.17	41.06
4 years	8	0.38	0.55	32.8	40.52
Under 5	767				
5 years and over	48				
All ages	815				

9. Previous SB deaths were as follows:-

1956	1,240	1959	1,224	1962	1,150
1957	1,214	1960	1,237	1963	1,007
1958	1,242	1961	1,222	1964	902
				1965	834
				1966	815

The 1966 total is 66% of that of 1956, showing a 34% reduction over eleven years.

10. On the official figure of 2,130 SB total births per year, each year sees an increase in the number of surviving cases as follows:-

Total SB cases		2,130
SB stillbirths	667	
SB deaths under 1 year	<u>694</u>	<u>1,361</u>
Surviving cases		769

From this figure must be deducted the number of SB deaths at the age of one year, or more.

11. INCIDENCE OF HYDROCEPHALUS IN SB DEATHS

a) Stillbirths

Total SB stillbirths	-	667
Total listed 'with Hydrocephalus'	-	567 = 85% of above

b) Deaths

Total SB deaths under five years	-	767
Total listed as 'Congenital Hydrocephalus'	-	147 = 19% of above

12. SCOTLAND

- a) Total births in 1966 98,125

On the basis of an incidence of 2.47 per 1,000, the number of SB cases in Scotland could be assumed as being 242 or 253 in 1965.

- b) Official figures relating to actual incidence of SB in Scotland are not available, but the following official figures suggest a higher rate of incidence than 2.47 per 1,000 total births.

SB Patients discharged from
hospitals in Scotland in 1965.

	<u>Male</u>	<u>Female</u>	<u>Total</u>
Under 1 year	142	134	276
1 - 14 years	106	80	186
15 - 24 years	3	3	6
25 - 44 years	6	7	13
45 - 64 years	2	-	2
	<u>259</u>	<u>224</u>	<u>483</u>

- N.B.
- 1) The term 'discharged' covers all discharges including deaths.
 - 2) These figures relate to discharges only and do not include those still in hospital.
 - 3) These figures do not include any SB stillbirths.

c)	<u>1965</u>	
	Total live births in Scotland	100,660
	Total Stillbirths	1,835
		<hr/>
		102,495

	<u>1966</u>	
d)	Total deaths from congenital malformations	658
	Total SB deaths	147 = 22.3% of above

13. NORTHERN IRELAND

Official figures available to date relating to SB and Hydrocephalus refer to the abnormalities only and not to the number of children. In other words a child who had both SB and Hydrocephalus is included under both headings.

a) Total births

1964	-	35,025
1965	-	34,550
1966	-	33,778

b) SB Hydrocephalus Cases

Abnormalities in children born.

	<u>1964</u>			<u>Rate per</u> <u>1,000</u> <u>Total Births</u>
	<u>Live</u>	<u>Still</u>	<u>Total</u>	
SB	109	30	139	4.0
Hydrocephalus	50	31	81	2.3
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	159	61	220	6.3
	<hr/>	<hr/>	<hr/>	<hr/>

	<u>1965</u>			<u>Rate per</u> <u>1,000</u> <u>Total Births</u>
	<u>Live</u>	<u>Still</u>	<u>Total</u>	
SB	108	25	133	3.8
Hydrocephalus	40	33	73	2.1
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	148	58	206	5.9
	<hr/>	<hr/>	<hr/>	<hr/>

1966

	<u>Live</u>	<u>Still</u>	<u>Total</u>	<u>Rate per</u> <u>1,000</u> <u>Total Births</u>
SB	84	26	110	3.2
Hydrocephalus	49	29	78	2.3
	<u>133</u>	<u>55</u>	<u>188</u>	<u>5.5</u>

Although the total number of children born in these years with SB/ and/or Hydrocephalus cannot be deduced from the figures, it is a legitimate inference that at the lowest interpretation, i.e. presuming that each child concerned suffered from both SB and Hydrocephalus the incidence of total SB births would still be greater than the official figure of 2.47 per 1,000 total births quoted for England and Wales in 1966.

ASSUMPTIONS BASED ON AN INCIDENCE OF 3.0 PER THOUSAND TOTAL BIRTHS.

- a) Total births (fact) 863,066
SB births (assumption) 2,589
- b) SB stillbirths (fact) 667
SB Livebirths (assumption) 1,922
- 2,589
- c) Death and survival rates assuming
 - 1) Total SB births 2,589
 - 2) Total SB livebirths 1,922
 - 3) As in paragraph 5 c).

		<u>SB Deaths</u>		<u>SB Survival Rates</u>	
	<u>No.</u>	<u>%</u> <u>SB Total</u> <u>Births</u>	<u>%</u> <u>SB Live</u> <u>Births</u>	<u>%</u> <u>SB Total</u> <u>Births</u>	<u>%</u> <u>SB Live</u> <u>Births</u>
Stillbirths	667	25.7	-	74.3	-
Under 1 year	694	27.0	36.0	47.3	64.0
1 year	45	1.7	2.3	45.6	61.7
2 years	12	0.46	0.6	45.14	61.1
3 years	8	0.3	0.4	44.84	60.7
4 years	8	0.3	0.4	44.54	60.3

- d) On this basis, the number of survivors each year would be as follows:-

Total SB births	-	<u>2,589</u>	2,589
SB stillbirths	-	<u>667</u>	
SB deaths under 1 year		<u>694</u>	
			<u>1,361</u>
			1,228

From this figure of 1,228, the total of those dying over the age of one year is to be deducted, (See page 3, paragraph 10).

15. Research carried out by ASBAH'S medical advisers points to the following conclusions:-

- a) The total number of SB patients alive today in the United Kingdom would appear to be at least 8,000, and possibly more than 10,000.
- b) The total number of SB cases born each year in England and Wales would appear to be in the region of

Hydrocephalus not associated with Spina Bifida	500
Spina Bifida with or without hydrocephalus	2,000
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	2,500
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- c) If correct, these figures lend support to the assumption of a total incidence of 3.0 per 1,000 total births, as made above.
- d) The total number of SB cases reaching school age each year would appear to be in the region of at least 850.

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