

Rubella aftershock

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Many parents are only too aware that people affected by congenital rubella syndrome (CRS) can develop new problems as they get older. Norman Brown introduces this important area of research.

For a long time, it was thought that the effects of the rubella virus could be seen principally in young deafblind children - and mainly through its effect on the primary senses of vision and hearing (McInnes and Treffry, 1982).

In fact, congenital rubella syndrome (CRS) can cause a range of effects. Before the introduction of the rubella vaccine, it was the greatest preventable cause of deafness alone. And many other children, who were apparently only mildly affected by the virus probably went largely unnoticed.

Among those children who were identified as having special needs as a result of CRS, it was noted that further damage became apparent as they grew older - with degeneration of faculties and the emergence of fresh difficulties in early adolescence and adulthood (Desmond et al., 1985; O Dea and Mayhall, 1988; Van Dijk, 1991).

Behavioural problems

Deterioration of hearing, late onset of eye problems and endocrine abnormalities were identified, even among people who had appeared to have escaped major damage when children. Changes in behaviour were often the result of physical changes but it was also questioned whether the control of emotion was directly affected as well. It is the emergence of behavioural difficulties which causes the greatest problems to families and service-providers. Sense believes that these behavioural disturbances may often be the expression of physical changes which could be ameliorated if correctly diagnosed and understood.

Other physical problems

It is not clear whether the late manifestations of rubella are solely the effects of the prenatal attack by the virus revealing itself through maturation and ageing; or whether the virus continues to live in the organs and insidiously attacks bodily functions throughout the individual's life. A strong body of opinion supports the suggestion of Ziring et al. (1977) that the early assault on the embryonic immune system damages the auto-immune responses themselves, with gradual but injurious effects upon the body's systems.

What we do know is that the young victims of the rubella virus experience a higher incidence of certain medical conditions in comparison with the rest of the population. Although not completely representative, because it focused upon severely affected deafblind individuals, a study conducted by the Helen Keller National Center in New York 1989-1991 (O'Donnell, 1996) generated some surprising statistics. O'Donnell's survey found not only abnormally high rates of deafness, blindness, and deafblindness but also:

- 30% of the sample developed glaucoma (general population rate of 0.5%);
- 52% had cardiac problems;
- 5.7% developed diabetes (20 x the general population), and 6.8% had thyroid problems, and a significant incidence of seizures and ataxia were also reported.

International comparisons

A survey of a similar group conducted in Canada 1997-1998 (Munroe, 1999) reveals a similar wide range of degenerative conditions. Munroe found 20.8% reporting glaucoma, 30% reporting the occurrence of seizures, 12.1% with diabetes and 10% with thyroid dysfunction. Among other changes identified were significant deterioration in hearing (24.1%) and in behavioural disturbance (23.2%).

In 1988, Sense, conducted a brief anecdotal survey of adults within its own and other organisations' residential services (Brown, 1989). The findings were similar, but not identical, to those reported in the USA and Australia. Since that time, changes and degeneration have been observed among people with congenital rubella by Sense residential service-providers and by family members served by Sense. This highlighted the need for a detailed investigation into the UK population to

identify the similarities and differences from those people affected in other countries.

There are certain significant differences between the different studies which mean that we cannot make direct comparisons. This may indicate virus mutation between countries or epidemics, or other factors as yet unknown. For example,

Australian studies showed that 30% of people between the age of 10 and 30 had diabetes, whereas studies in the USA revealed an incidence of 20% (Shaver et al., 1985) and, later, 5.7% (O'Donnell, 1996). Brown (1989), in a simple anecdotal survey of congenitally deafblind young adults in residential provision in the UK, found the incidence of diabetes not significantly different from that of the general population, although evidence from the National Congenital Rubella Surveillance Register (NCRSR) now questions that conclusion.

What has not been explored in any of these studies is what has happened to people with less severe manifestations of congenital rubella - although the NCRSR may allow us to remedy this.

National Congenital Rubella Surveillance Programme

The National Congenital Rubella Surveillance Programme (NCRSP) was set up in 1971 at the Institute of Child Health to establish a baseline of the annual incidence of congenital rubella defects in Great Britain, and to monitor the effectiveness of the newly introduced immunisation programme. Cases were reported to the NCRSP by audiologists, community and hospital doctors and microbiologists. In 1989 the reporting system was enhanced by the inclusion of congenital rubella on the monthly reporting card of the British Paediatric Surveillance Unit.

Once reported to the NCRSP, children with confirmed congenital rubella infection became part of the congenital rubella register. From 1989 to 1995 the Medical Research Council (MRC) funded the NCRSP to study the long-term results of congenital rubella, including the progression of visual and hearing damage and early-onset endocrine disorders.

Since 1995, when the MRC funding ended, support through the Public Health Laboratory Service has enabled the continued registration of new cases. However, long-term follow-up is no longer funded, and has been suspended.

Innovative investigation and research has already started in Nordic countries which it is hoped can link into research here. In the meantime, Sense and the Institute of Child Health are currently seeking funding to reactivate research which could use both Sense's and the NCRSP's data and resources.

Rubella is still a scourge world-wide and is not completely controlled, even in the United Kingdom. Congenital rubella is still the largest identifiable cause of disability among Sense's adult residential service users and we have an ongoing responsibility to continue the search for understanding and effective action to improve life's quality for all those who have been affected by the virus.

Key points

- Many people affected by CRS develop new problems as they get older
- Behavioural problems are common
- Research around the world shows regional differences
- Sense is campaigning for funds for further research in this area.

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