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ABSTRACT

Symptoms and characteristics of rubella (German measles) are listed, including a brief history of the disease. Emphasized are the effects of maternal rubella, particularly if contracted during the first three months of pregnancy. Likelihood of abnormalities of the child are detailed, and resulting educational as well as medical problems are discussed. Social repercussions of these handicapped children are noted. Existing legislation related to the problem is reviewed, and figures presented as supportive information relate to the incidence of rubella-caused handicapped children. (KW)

REPORT ON RUBELLA and HANDICAPPED CHILDREN

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Rubella, commonly known as "German measles," is a virus infection spread by droplets from the nose and throat expelled by a cough or sneeze. Most cases occur during the late winter and spring. The incubation period from exposure to rash usually is from 2 to 3 weeks; the rash persists for 2 or 3 days. Peaks of rubella outbreaks recur in 6 to 9 year cycles. There have been major outbreaks recorded in each of the past three decades with an epidemic of major proportions in 1934-35. The most recent epidemic was that of 1964-65.

One attack of rubella usually confers permanent immunity. Most reported cases occur in school age children. Only 15 percent of children are immune by the age of school entry, but at the time of adolescence the rate is 74%, and during adult years the immune rate reaches a plateau of 90%. In 1964, about 85% of pregnant women were immune to rubella with the number rising to 89% after the epidemic. Rubella is characterized by rash, slight fever, swelling of lymph glands in the neck and sometimes cough, headaches and swollen joints. It is generally less severe than rubeola, called the red or common measles, and may occur even without rash or other symptoms. It was long thought to be one of the most benign diseases of man.

The primary concern for rubella stems from the probability that a pregnant woman who has contracted rubella will give birth to a child deformed or stillborn. Rubella virus, after passing through the placenta into the fetus, presumably produces its damage by attacking the developing tissues and killing some of the growing cells. Thus different parts of the infant's body are affected depending on the stage of pregnancy at the time of disease. Generally, the earlier rubella occurs in pregnancy, the more likely damage is to occur and the more serious the potential damage.

If rubella infection occurs during the first month of pregnancy, there is a better than 50% chance that the child will be abnormal. The chances decrease but still remain high during the next two months with the chance of a child having one or more serious malformations of 20% with rubella during the first three months of pregnancy. During the second three months of pregnancy, there is still a 10% chance of abnormality.

Although rubella was formally identified as a disease entity separate from common measles and scarlet fever in 1881, it was not until 60 years later that Dr. Norman Gregg, of Australia, observed the relation between congential defects in babies and maternal rubella early in pregnancy. It was another 20 years, in 1962, before the rubella virus could be identified and cultivated so that it could be studied effectively. From these studies, experimental vaccines were developed in 1965, and were tested extensively on animals. In 1967, clinical trials with humans were followed by open population studies. This year, 1969, a vaccine has been licensed by the Federal government and a campaign, second only to the drive to eradicate polio in the mid-fifties, is now being mapped to terminate the ravages of rubella.

But this is only the introductory chapter in the story of rubella. There

is yet to be described the massive medical, educational and social problems left in the path of this disease. The major work is still to be done.

If the child of maternal rubella survives the critical newborn period with its hazards of congestive heart failure, anemia, and various infections, he may continue to be a medical problem for a number of years or for the rest of his life. Heart conditions, often in the nature of patent ductus, can be expected in about half of these children and continued care or surgery may be required. About one-third will have significant vision problems for which surgery, medication, or corrective procedures will be considered. Cataract is the most frequent eye disorder with a high percentage of bilateral cataracts to be expected, but some cases of glaucoma may be present, also. Hearing disorders, of the sensorineural type, may occur in more than two-thirds of the children, and the careful selection of hearing aids will be needed. But studies also show these children are more susceptible to middle-ear infection with continued need for otologic care. In general, these children will be more vulnerable to disease, less accelerated in their rate of growth, and require long-range medical management.

As great as the medical problem is, the educational problem is even more profound. These children as a group present characteristics which severely restrict their opportunity to learn. They are generally physically weaker and thus less able to maintain a sustained learning effort. Their impaired sensory systems of sight, and hearing limit use of the usual channels of learning. Their basic capacity to learn may be impaired with specific learning disabilities or general mental retardation. These separate disabilities, which present special problems in themselves, are frequently (about 54% of the time) found in combinations in children with a history of maternal rubella compounding the educational problems. In addition, the nature of the damage of these children makes the learning problem pervasive to almost all of their behavior, including the basic life activities as well as the traditional academic pursuits. As a result of the cyclical nature of the viral disease, these children are present as a large group at about the same age, which must be accommodated by the school system with facilities and program altered as the group grows older and requires a different learning environment. Finally, the educational problem is not one which will clear up quickly; it is likely to persist throughout much of the child's life from preschool through training for a vocation.

The results of rubella epidemics constitute a major social problem in the United States, The cost to society will be in billions of dollars. From data available, we estimate there are 20,000 to 30,000 additional handicapped children in this country as a result of the rubella epidemic which occurred during 1963, 1964 and 1965. Most of these children will have sensory impairments. We estimate that the population of children with rubella associated birth defects will include 12,000 children with significant hearing loss, 5,500 children with severe visual impairment, another 1,250 children with combined vision and hearing impairment, and 1,250 children with severe mental retardation and/or neuro-

muscular disorders. There may also be an additional 10,000 children with mild to moderate handicaps, including children with specific learning disabilities, children considered educable mentally retarded, and children with mild sensory impairments. At the present cost of educating handicapped children, we estimate that costs for 13 years of basic special education for these children will be over $1 billion. If the needed special education is not provided, many of these children will have to be institutionalized for life; the cost of such care for only half of these children would be nearly $3 billion. Added to these costs of education and care, will be the high costs of long range medical care for many of the children including the costs of hearing aids, glasses, and other prostheses.

In addition to these new costs which society must meet, there are the critical social repercussions that handicapped children can have on families. The added burden of new expenses, the possible need to move from the home community to a new residence near special services, the task of seeking understandable advice and effective services from a wide variety of specialists in child care and rehabilitation, the increased difficulty in raising a handicapped child, the possible embarrassment from the well-meaning acts of friends and neighbors who do not understand the handicapped child, the need to pay more family attention to the handicapped child than to the other non-handicapped children in the family—all these factors can have a devastating effect on the family relationship. Broken homes may follow with resultant welfare costs and added social problems.

Our efforts to meet and solve these great problems of our society should be joint ones. Medicine through its professional organizations, private practitioners, and through the National Institute of Allergy and Infectious Diseases of the U.S. Department of Health, Education, and Welfare, is deeply involved in the critical task of preventing further epidemics of the disease. They must select and license the best possible rubella vaccine, mass produce millions of doses for immunization, determine priorities for administration of vaccine, develop the administrative machinery for a massive program of immunization, prepare the public for this program, and develop procedures for evaluating the long-term effects of rubella vaccine and the immunization program. They are working under an ever present sense of urgency. The year 1970 is just around the corner and another increased outbreak of rubella is predicted early in that decade.

Special education through its professional organizations, its private and public schools and clinics, its state and local departments of education, and through the Bureau of Education for the Handicapped of the U.S. Department of Health, Education, and Welfare, is also working under a sense of urgency. The children with rubella related birth defects from the 1964 epidemic will soon be five years old and ready for formal school programs.

Public Law 90-247, signed into law on January 2, 1968, established part C of Title VI of the Elementary and Secondary Education Act, providing for the establishment of a number of regional centers to serve deaf-blind children

throughout the country. During 1969, eight of these centers will be operating or developing toward operation to serve deaf-blind children in 40 states. Their services will include diagnosis and periodic evaluation, special education and therapy, and consultation for parents and staff. The centers will utilize and coordinate those services already available in their area of service and develop new services where they are needed. Training for professional and supportive personnel, dissemination of information to the professional and lay public, and research may be included in the work of these centers. During 1970, two other centers may be developed to serve the remaining 10 states.

In September 1968, the President also signed Public Law 90-538, the Handicapped Children's Early Education Assistance Act. This legislation, recognizing the need for an orderly development of many new pre-school programs for handicapped children, provides for model programs to be set up throughout the United States for various kinds of handicapped children. These models will demonstrate ways of bringing help to handicapped children in both urban and rural areas at the earliest possible age.

Public Law 90-247, also amended Title III of the Elementary and Secondary Education Act to insure that the handicapped would be included in the development of innovative programs and supplementary services. Through this act, a number of centers giving diagnostic, educational, therapeutic and consultation services to children and teachers have been established to serve handicapped children in a number of states.

In addition, Public Law 90-247 also provided for the establishment of regional resource centers for the improvement of education for handicapped children, under provisions setting up part B of Title VI of the Elementary and Secondary Education Act. These resource centers will provide exhaustive diagnosis and evaluation for children with special learning problems and make recommendations for appropriate educational-therapeutic procedures to be used in their home community.

In addition to these special legislative acts, the Bureau of Education for the Handicapped has considered the problems of many new handicapped children from the rubella epidemic in developing programs in its Research Division and its Training Division. Information on any of these programs may be obtained by making a request to the Bureau at the following address:

Bureau of Education for the Handicapped, Office of Education
7th and D Streets, S.W.
Washington, D.C. 20202

The Bureau of Education for the Handicapped is now maintaining close contact with the National Communicable Diseases Center in Atlanta, Georgia. Information from this center can provide an "early warning system" for those in special education and rehabilitation. We must be vigilant for new disease epidemics and be prepared for effective cooperative planning to meet the new problems they bring.

SUPPORTIVE INFORMATION

Incidence of Handicapped Children

During 1964, there were 4 million live births in the United States, an average of 333,333 each month. To maintain the pace of 333,333 live births each month, during any given month there should be expected to be 333,333 expectant mothers in the first month of pregnancy, 333,333 in the second month of pregnancy, and the same number in each of the third, fourth, fifth, sixth, seventh, eighth, and ninth months of pregnancy. The rubella epidemic of 1964 was at its high during a four-month period from March through June. During this time 3,000,000 different women would have been in their first six months of pregnancy. It is estimated that at least 3.6%[1] of pregnant women contracted rubella during this period, so that 108,000 women (3,000,000 x 3.6%) would have contracted rubella during the first six months of pregnancy. The probability of severe fetal damage with maternal rubella during the first six months of pregnancy is estimated at 15% (20% the first trimester and 10% the second trimester). Fifteen percent of the estimated 108,000 women who would have contracted rubella during the first six months of pregnancy suggests the probability of 16,200 (108,000 x 15%) live births of babies with severe rubella related birth defects from the 1964 rubella epidemic.

The incidence of rubella during 1963 and 1965, though apparently not as high as in the peak year of 1964, was higher than usual and contributed to the number of babies with rubella related birth defects. We estimate that the high incidence during those two years combined resulted in no less than one-fourth the number of damaged children estimated from the 1964 epidemic, or approximately 4,000 more children with rubella related birth defects. The totals of 16,200 children from the 1964 epidemic and the 4,000 children from the combined 1963 and 1965 periods of high incidence yields a grand total of 20,200 children with rubella related birth defects.

The estimate of 20,000 handicapped children from the epidemic of rubella that swept through the United States during 1963, 1964, and 1965 is probably a conservative estimate for the following reasons. First, although the rubella epidemic of 1964 was at its high during the four-month period from March through June, the rising incidence actually covered a period of six months, with a rise beginning in January and increasing during February of that year. Second, the estimated proportion of expectant mothers who contracted rubella (3.6%) during this time is based on confirmed cases; with mild symptoms of rubella in the adult female, it is reasonable to expect that a number of cases of maternal rubella went undetected. Third, the probability that 15% of live births associated with maternal rubella during the first six months of pregnancy will result in children with rubella related birth defects is based on studies of children with severe handicaps which are observable early in the child's life. It is highly prob-

[1]Sever, J. L., Hardy, J. B., Nelson K. and Gitkeson, M. R., "Epidemiological Observations of Rubella in the Collaborative Perinatal Research Study," Proceedings, International Conference on Rubella Immunization, Feb. 18-20, 1969, p. 52.

able that many children with a history of maternal rubella will have handicaps which are mild to moderate and which would not show up until they have failed to learn what is expected in our culture.

Considering these factors and the estimates based on known statistics and predictive factors, the estimate of 20,000 to 30,000 handicapped children resulting from the 1963, 1964, and 1965 epidemic of rubella appears to be reasonable.

Educational Costs

Of 20,000 children, one-third will have visual impairment, two-thirds will have hearing impairment; 1,250 of these will have a combination of vision and hearing impairment. The remaining 1,250 will not have sensory impairment but will be severely retarded and some will have significant neuro-muscular disorders. The additional 10,000 children will have mild to moderate handicaps that may not be apparent when the child is very young.

Costs of educating a child with visual impairment average $3,498.86 annually; for a hearing impaired child, $2,910.93 annually; for a deaf-blind child, $14,000* annually, and for a mentally retarded child, $2,774.00 annually. These costs are based on the average annual cost per pupil in 1966-67. Costs for 13 years of basic special education are listed below:

Handicap	Number Children	Cost/Year Education	No. Years Education	Total Cost Education
Visually Impaired	5,500	$ 3,500	13 years	$ 251,250,000
Hearing Impaired	12,000	3,000	13 years	468,000,000
Deaf-Blind	1,250	14,000	13 years	227,500,000
Retarded/Crippled	1,250	3,000	13 years	48,750,000
Mild-Moderate	10,000	2,000	13 years	260,000,000
	30,000			$1,255,500,000

Institutional Costs

Average cost of institutionalizing a child for life without education is $180,000, each. This cost times 15,000 children (half of rubella group) totals $2,700,000,000, or more than three times the cost of educating a child to help him become a productive citizen to the limit of his capabilities.

*Based on Current Costs at Perkins Institute