CONGENITAL MALFORMATION SURVEILLANCE SYSTEM BASED ON VITAL RECORDS

Samuel Milham, Jr., M.D., M.P.H.

ONE of the most interesting facets of the recent thalidomide tragedy was the long interval between the appearance of a substantial excess of drug-induced malformations and the time of withdrawal of the drug from the market. According to Taussig's description of the West German experience, this interval was at least 1 year (*1*). In retrospect, it is easy to understand why such a long delay occurred. Although this excess of malformations was large in total number of cases, it was distributed both geographically and temporally in the total population of births occurring in this interval. The chance that any one physician would see a large number of the cases was, therefore, small.

Birth and stillbirth certificates filed at the New York State Department of Health have contained an entry for reporting congenital malformations since 1940. Analyses of the data, however, were sporadic (*2–5*), and no routine or continuous appraisal had been undertaken. Consequently, in May 1962 the department established a congenital malformation surveillance system based on vital records.

Method

In upstate New York (New York State exclusive of New York City) all birth certificates are sent monthly to the State department of health at Albany from each local registrar of vital records. As part of the routine processing of birth and stillbirth certificates (also death and marriage certificates), each certificate is coded in preparation for keypunching. Since May 1962, the coding clerk has kept a list of the code numbers of each reported malformation (see list), and the number of the birth certificate on which the report was made. Each month a frequency tabulation of malformation code categories is prepared and analyzed.

The total malformation rate is computed monthly by dividing the total number of reported malformations by the total number of births (live births plus stillbirths) reported in the month. This rate is compared graphically with the 1950–60 average monthly malformation rate and with the monthly malformation rate for 1960 (fig. 1).

Each specific malformation code category is then compared graphically with the monthly 1960 experience by plotting the number of cases in each category on a series of graphs, one for each code category (fig. 2). Multiple malformations are noted, but only the lowest malformation code number is counted. Selecting the lowest code number was an arbitrary decision, but the lower codes usually represent the most severe malformations. If any malformation were to show an obvious excess, the corresponding certificates would be examined and an epidemiologic investigation carried out.

Discussion

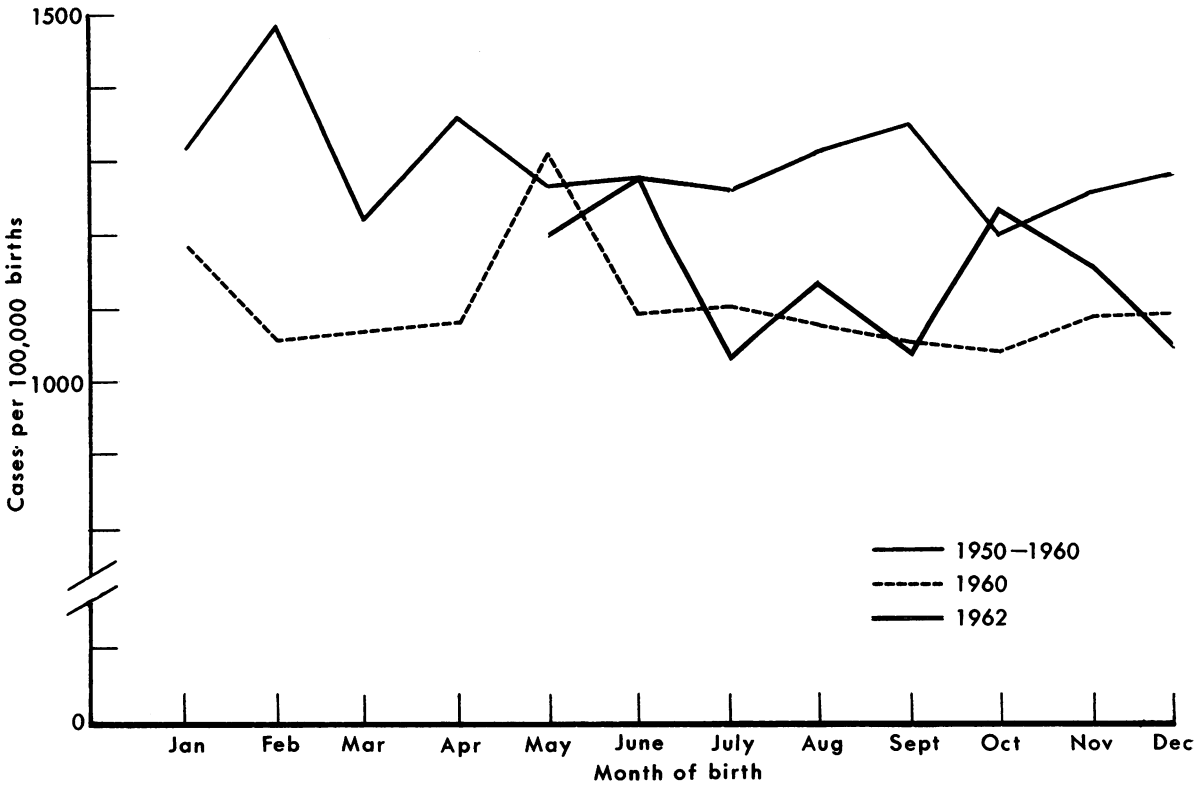
Birth records have a number of shortcomings as a source of malformation information. Malformations which are not readily apparent at birth, or which develop postnatally, are under-reported on birth certificates. Early fetal losses are also missed, but these are poorly enumerated by any record system. The great advantage of birth records is that information is available for almost the entire population at risk: 99.4 percent of births in upstate New

Dr. Milham is development consultant, New York State Department of Health, Albany.

Congenital malformation code categories used in malformation surveillance system, New York State Department of Health

Code No.	*Central Nervous System Malformations*
10	Anencephalus, acephalus, acrania.
11	Spina bifida, spinal fissure, rachischisis.
12	Hydrocephalus, internal, external.
13	Spina bifida plus hydrocephalus.
14	Meningocele, meningoencephalocele, meningomyelocele, myelocele, encephalocele.
15	Microcephalus.
16	Eye agenesis, anophthalmos, buphthalmos.
17	Congenital cataract.
19	Aplasia, dysplasia of brain, any part, eye, nervous system, spinal cord; hemicephalus, exencephalus, monster—nothing else stated.
	Cardiovascular Malformations
20	Tetralogy of Fallot.
21	Patent ductus arteriosus.
22	Interventricular septal defect (except tetralogy of Fallot).
23	Interauricular septal defect (patent foramen ovale).
24	Other unspecified and specified malformation of the heart.
25	Coarctation of aorta.
26	Other circulatory malformations.
	Gastrointestinal Malformations
30	Harelip, and/or cleft palate; congenital cleft lip, palate, or uvula; cheiloschisis, palatoschisis, labium leporinum.
31	Pyloric stenosis, hypertrophic pyloric stenosis, stenosis; congenital stricture of pylorus.
32	Imperforate anus, absence of anus or rectum, occlusion of anus, stricture of anus, atresia ani, atresia of anus or rectum.
33	Tracheo-esophageal fistula, esophageal stricture, congenital; esophageal atresia.
34	Umbilical hernia, exomphalos, omphalocele, evisceration.
35	Diaphragmatic hernia, herniation of abdominal contents into thorax.
36	Other malformations of digestive system, meconium peritonitis.
	Genitourinary Malformations
40	Epispadias.
41	Undescended testicle.
42	Polycystic disease of kidney, cystic kidney, fibrocystic kidney.
43	Extrophy of bladder (urinary), extroversion of bladder.
44	Other congenital malformation of any external genitourinary organ: absence, atresia, deformity, displacement, hypoplasia, male or female; hermaphroditism, pseudohermaphroditism, anaspadias, anorchism, polyorchism.
45	Other congenital malformation of any internal genitourinary organ: absence, atresia, deformity, displacement, hypoplasia, male or female; congenital hydroenphrosis, stricture of urethra, horseshoe kidney, patent urachus, persistent Gartner's duct.
46	Hydrocele.
	Malformation of Bones and Joints
50	Supernumerary digits, polydactyly, extra or accessory fingers or toes.
51	Adactylism, absence of digits or parts of digits.
52	Absence of arms or legs or parts thereof (except digits), absence of radius, ulna, humerus, tibia, fibula, femur.
53	Syndactyly, fusion or webbing of fingers or toes.
54	Achondroplasia, chondrodystrophy, dwarfism.
55	Club foot: talipes equino varus, valgus; calcaneo valgus, varus.
56	Congenital dislocation of hip.
57	Brittle bones, osteogenesis imperfecta.
58	Other malformation of bone or joint: hallux valgus, eversion of feet, flat foot, scoliosis, absence, malformation, displacement, or deformity of any bone or joint not classifiable above; absence of chest wall.
	Miscellaneous Malformations
60	Hemangiomata, nevi, or birthmarks.
61	Other malformations of skin.
62	Malformation of muscle, congenital malformation of muscles, tendons or bursae, muscle atrophy at birth.
63	Congenital malformation of respiratory system: absence of lung or part of lung, absence of nose, absence or malformation of any part of respiratory system (excluding tracheo-esophageal fistula), cystic disease of lung, atresia of trachea or larynx (thyroid cartilage).
64	Albinism.
65	Hernia of abdominal cavity (excluding umbilical hernia, omphalocele, and diaphragmatic hernia), inguinal, scrotal, ventral.
66	Tumor, mass or growth.
67	Siamese twins, conjoined twins, syncephalus, thoracopagus, ischiopagus.
68	Malformation, other specified, absence of thyroid, thymus, branchiogenic fistula.
69	Malformation, type unspecified, maldevelopment.
84	Mongolism.

Figure 1. Total congenital malformation rate, by month, upper New York State, 1950–60, 1960, and 1962



York take place in hospitals and more than 90 percent of the birth certificate entries on malformations are completed with a negative or a positive response.

Coding of the reported malformations is a critical step in the surveillance. A code which is too general will obscure small increases which are limited to a single code category. On the other hand, a code which is too specific will be unwieldy.

The malformation code which we have been using routinely since January 1962 was developed in recent studies of reported malformations (*4, 5*). It is a modification of a code used since 1950 in this department.

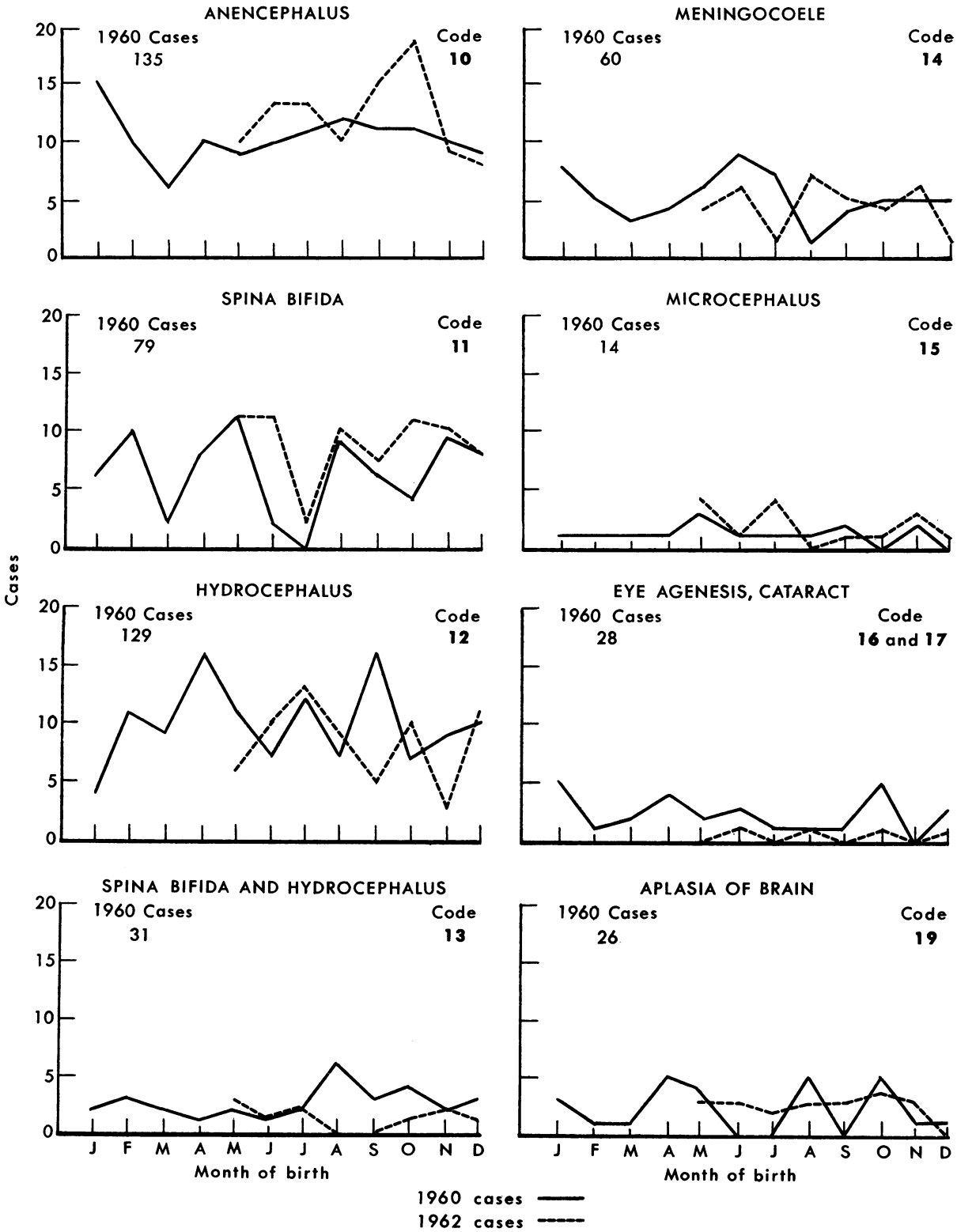
Since the number of births in recent years in upstate New York shows only minor fluctuations by month, a numerator, or case count, seems adequate for surveillance. Moreover, so few cases are reported in some categories that rates would give meaninglessly small results.

Analysis of malformation trends in upper New York State reveals one fact that is of central importance in surveillance. In the past 10 years, no reported malformation has shown a sustained increase. In this context, an observed increase in a malformation category would seem all the more important.

Granted that a surveillance system will quickly detect an excess in malformations, followup is all important. Someone has to be responsible not only for examining the surveillance data but also for determining the basis of any apparent increase in cases.

Fortunately, the revised malformation code is fairly specific for phocomelia. A separate code category (No. 52 in list) counts cases with absence of arms or legs or parts thereof (with the exception of digits). An excess incidence of phocomelia in our jurisdiction would not be unexpected, since some New York State physicians were given thalidomide for use on a trial basis. This situation will provide our surveillance system with a fairly rigorous test. All reported cases of phocomelia and amelia will be investigated for possible maternal ingestion of the drug. Results of this investigation will be reported later.

Figure 2. Sample sheet. Congenital malformation surveillance system. Number of cases of central nervous system malformations, by month, 1960 and 1962



REFERENCES

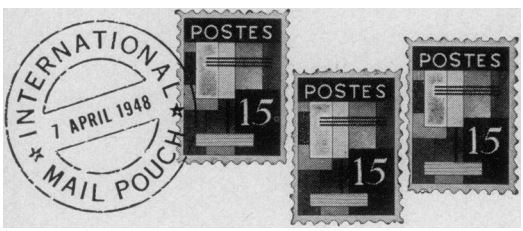
(*1*) Taussig, H. B.: Thalidomide—a lesson in remote effects of drugs [Editorial]. Am. J. Dis. Child. 104: 111–113 (1962).

(*2*) Gentry, J. T., Parkhurst, E., and Bulen, G. U.: An epidemiology study of congenital malformations in New York State. Am. J. Pub. Health 49: 1–22 (1959).

(*3*) DePorte, J. U., and Parkhurst, E.: Congenital malformations and birth injuries among children born in New York State, outside of New York City, in 1940–42. New York J. Med. 45: 1097–1100 (1945).

(*4*) Gittelsohn, A. M., and Milham, S.: Declining incidence of central nervous system anomalies in New York State. Brit. J. Prev. & Soc. Med. 16: 153–158 (1962).

(*5*) Milham, S.: Increased incidence of anencephalus and spina bifida in sibs of affected cases. Science 138: 593–594 (1962).



Ratio of Physicians to Population

According to recent estimates, there was 1 physician for every 800 people in the United States, for 930 in France, for 730 in Germany (and incidentally for 420 in Israel), while in Liberia the ratio of inhabitants to physicians is 20,000, in Saudi Arabia 24,000, and in the Sudan 44,000.—JOSEPH HANDLER, *director of the division of public information, World Health Organization.*

Pakistan's Antimalaria Campaign

Pakistan is entering the third year of a 14-year malaria eradication campaign designed to protect the 40 million people in the Western Province and the 50 million in the Eastern Province. A $3.8 million loan from the U.S. Agency for International Development will finance equipment and drugs needed for eradication activities in 1963. Total cost of the effort for the third year is estimated at $7 million. Local currency costs, estimated at $3.2 million, will be financed from proceeds of sales of U.S. agricultural commodities to Pakistan, equivalent to $1.5 million, and $1.7 million in local currency funds of the Government of Pakistan.

The antimalaria campaign was launched in 1961 in areas of Pakistan inhabited by 1.5 million people. In 1963 spraying operations were started in additional areas with a population of 5 million. Various areas of the country will be covered in successive steps. A semi-autonomous malaria eradication board is carrying out the project under a cooperative agreement with the World Health Organization.

Foreign Aid and Technical Assistance

The term "foreign aid" has been used as an umbrella term for a variety of programs. Most people have the impression that the United States has spent far more on technical assistance than is the case.

The total funds for the post-Marshall plan programs up to 1962 were $47 billion, of which but $1 billion has been spent for technical assistance in training, health, education, and welfare.

The remainder was spent for military equipment, for the support of nations on the periphery of the Iron Curtain that had spent more on their own military effort than they could afford, and for developmental loans.

The American people also have an impression that the United States is the only nation that conducts any large-scale technical assistance programs.

This is not the case. Speaking at the annual meeting of the American Public Health Association in Miami Beach last October, Fowler Hamilton, former administrator of the Agency for International Development, pointed out that in 1961 the United States extended $3.4 billion in foreign aid, but that the Marshall plan countries, Japan, and others also extended $2.5 billion for the same purposes.

—Excerpted from an article by Howard A. Rusk, M.D., The New York Times, October 21, 1962.