

National
Organization of
Mothers
Of
Twins
Clubs, Inc.

SUBJECT:

RESEARCHER:

DATE:

Disabilities in Multiples

NOMOTC

March 2003 - September 2003

PURPOSE: The purpose of this survey is to assess the occurrence and types of disabilities in multiple birth children.

METHOD: A questionnaire was printed in NOMOTC's *Notebook* and a National Mailing. This survey was to be completed by a parent of disabled multiple(s).

BACKGROUND INFORMATION

A total of 106 surveys were received and were broken down as follows:

1. Type of multiples: Twins - 91 (86%) Triplets - 13 (12%) Quads - 2 (2%)
2. Zygosity of multiples: Identical -18 (17%) Fraternal - 78 (73%) Combination - 7 (7%)
Unknown - 3 (3%)
3. Gender of multiples: Male - 44% (42%) Female - 25 (23%) Male/Female - 37 (35%)
4. Age of multiples: Ranged from 5 months - 16 years. Most of the multiples were 1-6 years of age (72%)
5. Gestation of multiples: <36 weeks (27-35 weeks) - 63 (59%) 36 weeks - 15 (14%)
37 weeks - 8 (8%) 38 weeks - 17 (16%) 39 weeks - 0 40 weeks - 1 (1%)
6. Birth weight of multiples: Ranged from 1 lb. 1 oz. - 8 lbs. 7 oz. Most of the multiples weighed between 3 lbs. - 7 lbs. (82%)

RESULTS

1. Seventy-three of first-born multiples (69%) had a disability, while only 68 (64%) of second born multiples had a disability. Seven third born higher order multiples (HOMs) (46%) and one fourth born quadruplet (50%) had disabilities.
2. The multiple's disability was most often diagnosed at <1 month of age (24%) or after one year of age (35%). Five were diagnosed in utero.
3. Only 18% of the disabilities were determined to be of genetic origin, while 27% were unknown as to whether the disability had a genetic basis.
4. Fifty four of the multiples (51%) had a physical disability. More than half of those children with a physical disability had Cerebral Palsy (CP). Other problems included: congenital heart disease, Marfan Syndrome, non-specific neurological problems, absence of several bones, Spina Bifida and Russell-Silver Syndrome.
5. Only sixteen children (15%) had any hearing loss. The causes of the hearing loss were: Down Syndrome, otosclerosis, small ear canals, genetic cause, and frequent ear infections.
6. Seventy of the multiples (66%) had some kind of speech disability. Most of them had some speech delay, but some had more severe problems. Other causes of speech disability were: CP, hearing loss, vocal cord polyps, problems after a tracheotomy, cleft palate, and autism.
7. Five children (5%) were born with a missing or deformed limb.
8. Twelve percent of the multiples had been diagnosed with autism.
9. Seven of the multiples (7%) had Down Syndrome, a genetic disorder caused by an abnormality in chromosome 21.
10. Thirty-five percent of multiples had some sort of learning disability. Many were too young to determine if they had any learning problems. Most of them had developmental delays that caused their learning problems. Other reasons for their learning disability were: mild mental retardation, Attention Deficit Hyperactivity Disorder (ADHD), autism, visual problems, and dyslexia.

11. Only one child had Spina Bifida (myelomeningocele).
12. Eighteen children (17%) had some sort of heart defect. Some of the diagnoses were: coarctation of the aorta, Tetralogy of Fallot, and aortic involvement from Marfan Syndrome.
13. Twenty-five percent of the disabled multiples had cerebral palsy. Almost half of those with CP were Twin B (+ one Triplet C), while only one-third of Twin A's had CP. In seven twin pairs, BOTH of the twins had CP.
14. Many other medical problems/disabilities were also documented. Some of these were: Asperger Syndrome, kidney reflux, interventricular hemorrhage from Twin-to-Twin Transfusion Syndrome, torticollis, hydrocephalus, single kidney, vision problems, galactosemia, pulmonary stenosis, seizure disorder, cranial synostosis, channelopathy (Dystonic Tic Disorder), hypoplastic left heart syndrome, and Sensory Integration Disorder.

CONCLUSIONS

1. Prematurity, and resultant low birth weight, seems to be the main risk factors in multiples having a disability. More than half of the multiples in this study were born prior to 36 weeks.
2. The most common disability of the multiples was a speech problem. Most had speech delay, but some had more severe problems relating to such conditions as CP, hearing loss, and autism.
3. The next most common disability was a learning disability. This was mainly related to developmental delays, but other more severe problems existed also, including: autism, ADHD, visual problems and dyslexia.
4. The most common physical disability was CP. More than half of those multiple birth children with a physical disability had CP. More of the multiples with CP were Twin B rather than Twin A.
5. The other most common disabilities among the multiple birth children were: hearing loss, autism, Down Syndrome, and congenital heart disease.